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Gitte H. Koksvik

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Blurry lines and spaces of tension. Clinical-ethical and Existential issues in Intensive Care

A study of three European Intensive Care Units

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As rewarding as it has been to conduct and write this research, those who know me well, are also aware of how very dark these past few years have been for me. In so many ways, 2013 to 2016 were years of loss. Defending the present work therefore, I turn over a new leaf, excited – as out of character as that may be for a philosopher – for the future and that, which is to come.

Any and all shortcomings of the thesis are solely my responsibility.

Sincerely,

Gitte H. Koksvik

Summary

“Come on”, the medical student said, practically tugging my sleeve. “We’re gonna go talk to a patient. And he has AIDS! It’s super interesting.” We went in a hurry, a young doctor, two medical students, and myself, off to see the patient, and to evaluate whether or not to admit him to the Intensive Care Unit. Walking briskly down the halls of the ICU on our way to the next floor, it did feel, I reluctantly admitted to myself, rather interesting indeed.

I first entered the ICU as an observer for my Master thesis in philosophy in 2012, and then later in 2014 in connection with my PhD work. I had never experienced intensive care, and my expectations of the hospital were colored by typically Hollywood-ized television representations. Consequently, I expected an environment of glorious mayhem and constant dramatic action. Judging from the reactions I continue to get from friends and peers upon hearing about the object of my study, I suspect that their ideas are much the same as mine were. I have no medical or nursing training. Consequently, when I decided to do fieldwork in the ICU, not only did I receive a fair share of concerned looks; I was warned. On the one hand, there was the concern that such a topic might be awfully depressing. This is a tendency identified by several authors working on sensitive topics, especially end-of-life, or death (Hockey 2007). Concerns also centered on my physical well-being. A friend of mine who was an intern physician at the time cautioned me. Are you prepared for this? He asked. Prepared for the sights? The sounds? Indeed, it is no secret that the hospital, or any form of clinic, may confront the observer, next of kin, or the patients themselves with distinctly uncomfortable sights, sounds, and smells. Anyone who knows someone who has gone to medical or nursing school knows that fainting or vomiting are expected rites of passage during training, although this normally occurs in the surgical suite or by the autopsy table. As Kate Watson poignantly puts it, medicine (and I would add nursing) is “an odd profession in which we ask ordinary people to act as if feces and vomit do not smell, unusual bodies are not at all remarkable, and death is not frightening.” (2011: 43). Indeed, the medical gaze does not come naturally to most, and has to be achieved through training. Untrained as I was, I braced myself.

Much of the time, being an observer in the ICU means observing in the classical sense of the word: standing on the sidelines and *watching*. Being trained in philosophy, I planned to conduct a form of *epoché,* disregarding any nuisances in order to get to the 'real' information, and I was prepared to take steps to prevent any emotional or somatic reactions from endangering my mission of observation. They were *something* that needed to be overcome. I prepared for gruesome sights of blood and goo, and if there was one thing that I did not expect, it was to be bored. Arriving at the main adult ICU of a large Norwegian university hospital then, I found myself profoundly surprised. There was in fact hardly a sound. There was no running, no yelling—there was hardly any talking at all. Quiet control reigned in this country of sleeping patients. No fuss, no movement, no emotion, and no unnecessary words were uttered. I quickly adapted to the general mood of the place, and understood that loud noises and commotion would have been perceived as quite disrespectful.

As I moved from site to site, becoming increasingly familiar with the world of the ICU, I made a surprising and initially rather satisfying realization. The truth was that no amount of slime, bags of adult feces, blood and urine, open surgical wounds, necrotic skin, or amputated limbs had the appalling effect on me that I had anticipated. So little in fact, that I on several occasions felt prompted to lie to staff when they rhetorically questioned me, saying, "How hard it must be for you to be here." Somehow, it felt like an insult to them if I told the truth that no; it did not really bother me.

I was relieved that I managed to withstand feelings of nausea and disgust when faced with things that are normally thought to be quite off-putting. And of course, had I fainted at the sight of these things, any fieldwork in the clinic would have been nearly impossible to carry out. Indeed, I concluded, not without certain smugness; I might have made an excellent surgeon. Nevertheless, this is not to say that I remained unaffected—in the most literal sense of the word—by the experiences of the ICU. By its very nature, the intensive care unit can be an overwhelming space. One student who had previously spent time in many other hospital units, at one point described coming there as receiving *a slap in the face.* I suffered feverish dreams every night for weeks, waking up freezing in a clammy cover of my own cold sweat. I started regularly eating more. On several occasions, I felt a distinctive burning sensation coming from within, resulting in cold sweat on my forehead, peering through the pores of my skin, my heart pounding seemingly in my stomach, eyeballs feeling too large for my eye sockets. Months after fieldwork was concluded, some of the people I had encountered continued to haunt my thoughts. Whilst observing, I frequently experienced the feeling of violating upon something, of performing some transgressive act by virtue simply of my presence.

The reason for this autobiographical note, is that herein indeed, lay the very center of my investigation. Conducting ethnographic research on a high-tech biomedical environment, the researcher comes face to face with an exotic world that simultaneously feels strangely familiar. In my earliest exploration of intensive care, my Master thesis entitled “Fully human, fully technical” (*Toute humaine, toute technique*) (2012), I argued that this branch of technology-heavy, high-performance clinical practice had the possibility to destabilize categories, not least with regard to human existential concerns. Nature and culture, technology and biology, body and person, subjectivity and objectivity, science and art, life and death, the secular and the sacred. Dealing with these realities involves a balancing act—a separation, and a bridging, of categories. There is a definite allure to intensive care. It is a place where sometimes awesome—in the very literal sense of the word—recoveries take place. Simultaneously, it incites fear.

This is a thesis about intensive care. It is about hospital work. It is about the closeness of life and death, and more generally about what it means to be human. The way care is practiced, and the ways in which death is enacted and talked about. The ways in which personhood takes form in this setting, and those for whom this category is restricted. All of these aspects reveal something about both the values of our society and of human resilience. In many ways I attempted in this thesis to work from the statement made by Foucault at the end of his “Naissance de la Clinique”, namely that if, in the biomedical era, medical scientists have been central to European culture, this is not due to their qualities as philosophers. It is because medical thought (la pensée médicale) engages intimately with the philosophical status of humankind (1966: 202).

In the spring of 2014, between January and June, I conducted a multi-sited fieldwork in three European intensive care units—in Norway, France, and Spain. I spent a month at each place. This research was spurred by my Master thesis work for which I did a three-week long fieldwork in Norway in 2012. Combined, these field experiences comprise the empirical basis of my PhD project. Although the dissertation belongs to the discipline of social anthropology, the project deliberately crosses disciplinary boundaries, combining practical philosophy and ethics with ethnographic methods. The working title of the project was "Clinical-ethical and existential issues in intensive care."

My PhD project has been a part of the interdisciplinary, international research program "The Cultural Logic of Facts and Figures" (CUFF), funded by the Research Council of Norway. The overall ambition of the CUFF project was to examine a number of contemporary modes of objectification, measurement, and standardization to see how they constitute a cultural logic and shape four main dimensions of social life: meaning/representation, morality, notions of thinghood, and notions of personhood (NTNU, n.d.).

It was decided already at the proposal stage of my work that I would write an article-based thesis. In an article-based project, each article stands on its own as independently published or publishable pieces of academic production, allowing for a different focus in each article. There is little precedence for writing article-based dissertations in anthropology. In a casual discussion with two experienced anthropologists, one of them suggested, referencing the classical anthropologist Clifford Geertz, that in fact, since the discipline developed *together* with the format of the monograph, the two indeed became intertwined, and the monograph become the very language, or script, of anthropology. Consequently, the arrival of the article-based thesis into this discipline presents a problem, because there is no script for it. No recipe. My colleagues' reasoning, in line with Geertz, resonated with me. Yet rather than see this lack of a script as a *problem*, I have chosen to view it as an opportunity to be creative. It is my hope, and intention, that the articles may take on a new richness and texture, through this preliminary part. Moreover, I would be delighted if my work could be a contribution to legitimating article-based thesis work within the discipline, and contributing to *changing and evolving* the script of anthropology.

The articles

The two first articles deal with “life in the ICU.”

The traditional Western category of the person presupposes a conscious, self-aware individual who possesses agency and who experiences both herself and the world around her. This is problematic in intensive care. In “**Silent subjects, loud diseases: Enactment of personhood in intensive care**” I look at the concept of personhood in the case of verbally inexpressive, typically unconscious patients or patients with a low level of lucidity. Employing Annemarie Mol’s framework of multiple ontologies and enactment of reality, this article problematizes some of the assumptions about depersonalization and dehumanization involved in intensive care practice. I discuss how a patient’s personhood may be enacted in both positive and negative ways through a multitude of practices including speech, touch, information gathered, as well as attention to machines and numbers.

“Dignity in Practice: Day-to-Day Life in Intensive Care Units in Western Europe” is an empirical investigation of how the concept of dignity is played out in real life. Dignity is a key ideal in contemporary health care ethics. However, the definitive meaning of the concept remains unclear in the academic literature, and some argue that it is a useless concept. My interview materials reveal very similar attitudes toward patient dignity across the three field sites. Nevertheless, in practice, different and possibly conflicting notions of what dignity means are engaged simultaneously in the care of critical patients. I borrow and adapt the terminology technology-in-practice from Timmermans and Berg (2003), in order to show how the ideal of patient dignity is carried out in practice in the daily life of the three units.

The third and fourth articles turn toward certain dilemmas and issues that emerge in the context of end of life and dying in intensive care.

In the third article, “**The Microethics of non-treatment decisions. Examples from European Intensive Care**”, I take on the much dealt with topic of withholding and withdrawing treatment. I see this as closely connected to the modern fear of futile or excessive treatment in medicine, which is unanimously considered harmful to human dignity. Oftentimes, the topic is dealt with employing the so-called "Four principles of bioethics" approach. I find these to be too abstract, offering little contribution to practice. Through ethnographic study, I show how non-treatment decisions (NTDs) are in fact reached—or not reached—through intricate, *microethical* processes. I identify what I consider to be important aspects involved in NTDs, such as a discomfort with death, the influence of next of kin, and physicians' own experiences. I suggest thatthere is a need for a standardization of NTDs in order to assure fair treatment to individual patients and so that medical personnel may feel comfortable with their practice.

Relatedly, article four: "**Medically timed death as an enactment of good death. An ethnographic study of three European Intensive Care units**" also deals with non-treatment decisions. In most cases, such decisions lead to the death of the patient in question. Both in the academic literature, and in lay perceptions, the technology heavy setting of the intensive care unit is portrayed in stark contrast to ideals of good or natural death. I have found, however, that nursing and medical personnel in the ICU tend to feel more comfortable with patients dying after a medical decision than when death is sudden, or that they consider these scenarios to be equal. In the article I explore possible reasons for this, and I show how medical and nursing personnel, through a variety of acts and meaning making rituals, attempt to enact a good death following non-treatment decisions.

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Article 1: Silent Subjects, loud diseases. Enactment of personhood in intensive care. *HEALTH: an interdisciplinary journal for the social study of health, illness and medicine* 20(2): 127-142

Article 2: Dignity in Practice: Day-to-Day Life in Intensive Care Units in Western Europe. *Medical Anthropology* 34(6): 517-532

Article 3: The Microethics of non-treatment decisions. Examples from European Intensive Care. Submitted to *Journal of Medical Ethics*.

Article 4: Medically timed death as an enactment of good death. An ethnographic study of three European Intensive Care units. Accepted for publishing by *OMEGA. Journal of death and dying*.

Part 1. Scientific medicine

In this section, I look at the empirical and theoretical framework within which my object of focus, intensive care medicine, is located. I do so by describing the character of biomedicine and very briefly outlining its history. This is important in order to understand and to flesh out some of the concerns and issues located within the field. Technology is of particular relevance here, both as biomedicine may be characterized as an example of technoscience in practice, and especially because intensive care is habitually referred to as a "high-tech" form of medicine. Strictly speaking of course, intensive care may be no more technologically infused than other domains of medicine—both clinical and otherwise. Indeed, technology in the widest sense is pervasive in contemporary living. Nevertheless, intensive care technologies have had a substantial impact on medicine and our culture by shifting the criterion of death, by creating states of survival that challenge our conceptions of personhood, and by blurring of the relationship between body and machine.

Scientific medicine

What we today call medicine, a vast domain of knowledge and activities aimed at promoting and restoring health and longevity in humans, is motivated by a set of fundamental values, namely that (at least some) human life is good and worth preserving and that it is good to alleviate pain and physical suffering. As Girard (1988) pointed out almost 30 years ago, there are two moral prejudices that are easily recognizable in modern medical interventionism: A view of illness as fundamentally bad and of death as the ultimate evil. Secondly, he contends, there is a strong positivism, characterized by optimism about the breadth, significance, and reliability of medical knowledge (1988: 29). Indeed, Komesaroff argues that the basic conception that has guided modern, Western clinical and medical ethics stems from the 17th century Enlightenment's belief in progress toward greater knowledge and social-moral improvement through the application of reason. The telos of science, Komesaroff writes, presented the liberation of humankind through mastery of nature—both external and internal (Komesaroff 2008: 7). This tendency is confirmed by Redfield's ethnographic study of Doctors Without Borders (2013), and comes across clearly in Timmerman's work on resuscitation technologies, in which he identifies what he calls *an ethos of life* in contemporary emergency medicine (1996: 768) It is no surprise that the World Health Organization's definition of health: "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO 1948), reads like a utopic state or a description of an *ultimate good*.

Throughout time and in many cultures, health promoting and -restoring activities fell under the domain of religion or magic. Toward the end of the 1700s however, a rupture occurred in Europe. Medicine went from being a traditional enchanted practice, to a discipline aiming for the coveted status of a natural science (Foucault 1966). Concomitant with the modernization and disenchantment of Europe, a new medical thought and practice emerged, the first scientific practice, as Foucault points out, in which humankind was to be both the acting subject, and the object, which was acted upon (1966). Adopting the mind-set and methods of natural science implied conceptualizing human life as purely immanent. New knowledge was produced about health management and the human body, the latter being situated in the domain of 'objectified nature' (Locke and Ngyen 2010: 32). This meant reducing humans or human life to intricate anatomical objects. This was the beginning of biomedicine as we know it today.

Scientific medicine and technology: a chicken and egg situation

> Technology has accompanied Western civilization like a shadow (Almerud-Österbeg 2010: 1).

Although some argue that technology must be seen as prior to science (e.g. Kemp 1996), it is generally assumed that science predates technology. The former is considered a pure, intellectual enterprise and a goal in itself, whereas technology is considered to be the exploitation of scientific knowledge for human gain. A crucial development took place in the early 20th century however, in which changes in mathematics and physics led to an increased closeness, or even confounding of science and technology in the service of human "progress," fusing theory and practice (Bachelard 1934).

Modern medicine was aided more than anything by a variety of new instrumental technologies, and regardless of the order, there is no escaping the symbiotic relationship between *knowing* and *doing* in scientific medicine. One such technology was the legalization and normalization of human dissection and autopsies. This practice had long been forbidden and severely taboo. The importance of this cannot be overstated. As many trace medical dualism back to Descartes' fundamental dichotomy of mind and matter, others, like Mol (2002), emphasize that it is not so much mind versus matter that is the question, as it is the *live body* versus the *dead*. In Mol's opinion, contemporary biomedicine traces back, not to Descartes, but precisely to this development of autopsies, and more specifically to the French surgeon Xavier Bichat. Operating in the high era of anatomical pathology, Bichat and his contemporaries established the medical paradigm in which autopsies emerged as an unrivalled source of knowledge of diseases and human physiology; the true reduction of the human body to a natural object. As Bichat famously expressed, life was simply the "sum total of the functions resisting death (Boch 2009: 27 my translation).

Another, less exotic but vital new practice was the use of statistics. Extended use of calculations had important consequences for prediction of disease and the development of epidemiology as well as a universalization of health concerns. It also led to a 'normalization' of bodies through large-scale comparison. Biological variations came to be understood as deviations from the norm, a norm that was statistically devised and based on the idea that human bodies were universally built the same (Locke and Ngyen 2010: 26, 32).

Hofmann identifies five key characteristics of today's technology-infused medicine, saying that it is *interventive, expansive, disease defining, generalizing,* and *liberating* (2001). Indeed, through technology, Hofmann asserts, medicine has gone from assisting nature's healing capacities to controlling and manipulating bodily healing. These interventionist qualities have expanded the field of medicine and increased medical specialization. Having developed ways of controlling organs, functions, and processes of the human body, we are now in a position to treat conditions for which there previously was no remedy. Medicine no longer simply—or mostly—explains: it *intervenes*, putting practice before theory. Technology influences medical action by defining what may be diagnosed, and what may be treated. This, moreover, is achieved by generalizable, scientific methods. Technology has dislodged medical knowledge from the subjective experience of the patient (2001: 336). The aspect of liberation corresponds well with the thought of augmenting human autonomy in the face of our own biological frailty and of the decrepitude of our bodies.

Technologies: enabling and troubling

The relationship we maintain with technology, however, not least medical technologies, is ambiguous at best, and there is a significant amount of unease with modern technological medicine, both in academia and in popular discourse (e.g. Lupton 2012; Sharp 2006). Pfaffenberg (1992) explains this dualistic attitude toward technology well, by likening what he calls “the standard view of technology” to the conception of the Hindu God Shiva, who in the Hindu tradition is both a revered creator and a feared destroyer.

> The result of the explosion of technological knowledge has been a massive expansion of Man’s reach, but with lamentable and unavoidable social, environmental and cultural consequences: we live in a fabricated environment, mediated by machines. Technology was more authentic when we used tools, because we could control them. Machines, in contrast, control us. (1992: 494)

Critics question not only many of the practices of biomedicine, but its very foundation (Ariès 1975; Illich 1976; Le Breton 2011). As the biomedical model is built on a reductionist view of human beings, grounded, as many hold, in the famous Western mind-body dualism (e.g. Leder 1984), or indeed in the opposition between living and dead bodies, a common criticism levied against contemporary forms of biomedicine, is that it disregards the complexity of humanity, and that it considers the patient not as a person, but as a mechanical corporal form in decline (Dupont 2007: 119, Le Breton 2007: 379). Modern biomedicine, critics argue, focuses exclusively on physical symptoms, forsaking all aspects of the patient's life-world, as it is driven by what Sharp identifies as "an overwhelming concern for the body's inner workings (2006: 9). In the essay, "*The sorcerer's broom. On medicine's rampant technology*" (1993), Cassell is deeply skeptical of the development of medical technologies, which he claims have gotten out of hand. Like the broom in "the sorcerer's apprentice," Cassell states, technologies take on a life of their own (1993: 32) much to the detriment of humans. As a class, he says, technologies spread faster than the ideas that inform them, something that Cassell attributes both to a self-perpetuating nature of technology and to certain traits of human nature that allow this to happen. Implicit in his line of reasoning, is the assumption that nature (both human and physical) originally lays at the root of the development of technology. Scheper-Hughes and Lock wrote already in 1987, referencing O'Neill, that "we have been 'put on the machine' of biotechnology, some of us transformed by radical surgery and genetic engineering into 'spare parts' or prosthetic humans." "Lives are saved," the authors continue, "or at least deaths are postponed, but it is possible that our humanity is being compromised" (1987: 23).

Nevertheless, *life* and good health today, some authors argue, stand out not only as a desire, but also as a perceived individual right in Western societies (Marin 2008; Redfield 2012). As Redfield writes, "we expect that people—even small children—will live" (2012: 157). Having conducted an ethnographic study of Doctors Without Borders for several years, Redfield writes, "Saving lives surely addresses living in the sense of biological survival, but not always life in the sense of living well or, as the expression goes, 'having a life'" (2012: 16). In Redfield's opinion, humanitarianism—which, according to Fassin (2011) is an important contemporary form of reason, is a *stopgap gesture,* which offers no comprehensive solution. "Lives are sustained and prolonged, more than they are 'saved' in any final sense" (2013: 17).

Despite criticism and reticence, we see that the reliance upon biomedicine to provide us with the answers to both social and medical problems is growing. As Lupton states, the faith in medicine remains a *creed* in Western cultures (Lupton 2012: 1, my emphasis). The importance of technological novelty and development today is such that technological curative functions may have become the very criterion by which progress in medicine is measured (Hofmann 2002: 157).

Intensive care and reanimation

Of the network of clinics, technologies, discourse, and bureaucracy that make up modern biomedicine, intensive care is a stellar example. Intensive care developed from the first artificial ventilation techniques employed during the polio epidemic in Denmark in the 1950s. Continuously more sophisticated ventilators, heart monitoring and resuscitation technologies, as well as technologies designed to monitor and palliate other vital functions, followed suit (Puri et al 2009: 195, Gómez-Rubí 2002: 25-27). Today, intensive care is a biomedical specialty in its own right, which incorporates and centers on organ and system supplying technologies. It caters to patients who are acutely and severely ill or injured, and who as a rule all suffer from life threatening, but assumed reversible conditions. In the intensive care unit, many if not most of a patient's organic functions are controlled or monitored by technological means. It is a place in which the patient passes a particularly critical stage in their illness, then returns to life as it were, either through exiting the hospital all altogether or, more commonly, being transferred to a "regular unit." The term employed for intensive care in French is telling. Here, the term is "réanimation"; from the Latin "anima" soul, and "re-" again, meaning *to return life,* or a *return of soul*. This is truly indicative of some of the things that take place in the ICU.

What does it mean to be reanimated?

> Your family member is admitted to the intensive care unit. All patients admitted to this unit are considered to have a serious prognosis and complications may arise, even in those patients who appear to be doing well. A specialized team consisting of medical and nursing personnel, auxiliary staff, as well as other qualified professionals cares for the patients. (Servicio de medicina intensiva. Información general. Generalitat de Catalunya, Department de Salut)[1].

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[1] My translation. Su familiar está ingresado en el Servicio de Medicina Intensiva. Todos los pacientes ingresados en esta Unidad se consideran de pronóstico grave, ya que pueden aparecer complicaciones incluso en aquellos que aparentemente están bien. Los pacientes están atendidos por un equipo especializado formado por personal médico y de enfermería, personal auxiliar y otros profesionales cualificados.

> Your next of kin is admitted in “intensive care” due to a medical situation, which necessitates momentary intensive surveillance. This may involve highly specialized technologies such as respiratory assistance, dialysis or circulatory assistance. For your first visit, do not enter the room alone. Do not hesitate to ask for explanations of anything that may appear new or difficult to understand. Your next of kin has a single room, and the equipment surrounding him serves the purpose of continuous surveillance. For reasons connected with the prevention of nosocomial infections (infections acquired at the hospital), your next of kin might be in isolation (Intensive care Left welcomes you. Information pamphlet, Central Hospital)[2].

Intensive care patients require constant, intensive, treatment and monitoring for various reasons. Multiple organ or systemic failures may occur as the result either of progressed disease, surgical complications, or indeed from various traumas resulting typically from accidents, acts of violence, or suicide attempts. As many as 80% of the patients may lack capacities for autonomy during their admission, many remain unconscious for periods or the entire length of the stay (Ruston, Palmer, et al. 2009: 3). Due to the critical condition of the patients, intensive care units have an elevated mortality rate. In Europe, this is estimated to be around 20% (Nimmo and Singer 2011). Normally, although there are exceptions, intensive care patients neither start nor end their hospital stays in the ICU. Patients usually enter through the emergency room, operating theatres, or other medical units. The objective of intensivists, doctors specialized in this form of treatment, is not to return the patient to health—although this is the ultimate objective of curative medicine. Rather, intensivists work on an “intermittent” goal to save the patient’s life in a time of crisis and to combat the acute criticalness of their condition. Thus, intensive care does not primarily treat co-morbidities or underlying disease. The goal of the ICU is to transfer the patients out again in better shape, and as quickly as possible. As one physician said, practically the moment they arrive, you start envisioning them leaving.

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[2] My translation. Votre proche est hospitalisé en « Réanimation X » pour une situation médicale nécessitant momentanément une surveillance intensive pouvant faire appel à des techniques plus spécialisées : respiration assistée, dialyse, assistance circulatoire… Pour votre première visite, n’entrez pas seuls dans la chambre, n’hésitez pas à vous faire expliquer tout ce qui vous semblera nouveau ou difficile à comprendre. Votre proche est dans une chambre seule et les équipements autour de lui servent à une surveillance continue. Pour des raisons liées à la prévention des infections nosocomiales (=acquises à l’hôpital), il est possible qu’il soit « en isolement ».

Ethical and existential issues: the field

Over the last few decades, the cultural and social aspects of medicine and medical practice have become more important in the social sciences and the humanities. Indeed, medical or clinical anthropology has been important in legitimating “at home” anthropology, and it may even have been, as some authors claim, a driving force behind *anthropologizing* the West (Lupton 2012: 8). An extensive body of work has been produced, focusing on patient’s backgrounds, their wishes, and experiences of illness and treatment. Likewise, as we have seen already, certain forms of treatment or prevention have become topics of research for social scientists who raise critical questions with regard to the motives behind medical discourses. In what follows, I deal with some such questions as they pertain more specifically to intensive care and my project. Re-conceptualized living

The body and the self

The relationship between nature and culture in medicine is a complex one because it operates on different stages.

In the ICU, the patient is very much a body of organs—or better still, organs enveloped in a body. The whole is not greater than its parts. The technological aspects are decisive for the ways in which care and treatment are envisioned and carried out. For instance, the most mundane tasks such as turning a patient can be intricate due to the many tubes and catheters connecting the patient’s body to the technology. “The patient becomes a body whose organs must be maintained,” writes Kentish-Barnes, “and this body in turn disappears behind the machines” (Kentish-Barnes 2008: 77).

> It is impossible to enter into the room of a patient receiving intensive care treatment without having the feeling of infracting on something that cannot be put into words. The

> abandoned body allows seeing that which ordinarily cannot be seen (Bergé 2010: 65. My translation).

What happens to the concept of being alive when we may support or even substitute human vital functions by technical means? Being kept "artificially alive" is an agreed upon harmful phenomenon. Yet one could easily argue that patients in the ICU are all kept artificially alive, at one point or another. When receiving intensive care treatment, patients are stripped down to their very corporeity, which is perhaps more blatantly exposed than in most units due to the suppression of consciousness and thus of any expressions of individuality. Furthermore, this exposed body is coupled with technology in ways more explicit than in many other places. The various apparatuses such as the syringe machine and the artificial ventilation through intubation are literally *incorporated* in the human. The quote above by French anthropologist Bergé, suggests that there is something *more* to the patient in intensive care than anonymization and dehumanization by technology. Generally, when one talks of something being difficult to verbalize or to articulate, our minds perhaps go to the arts or even to intense sensuous experiences. Here, however, it is not the experience itself that is hard to articulate—it is that which is experienced. It is that with which one comes into presence: a particular aesthetic. There is however, something quite impressive or awe-inspiring about a body whose every orifice is connected to machines by tubes, and whose every internal procedure and value is measured. The concept of a reflexive "I", that is, a mindful self that is independent of the body and of nature is essential to a post-Enlightenment approach to knowledge. In the West, person and individual are overlapping categories and this is problematic in intensive care when abilities for expression, rational thought, and agency are suppressed. Research shows that patients in the ICU oftentimes experience alienation, feel neglected, and not s*een* by the personnel (Almerud 2007). As much as 80% of patients experience drug induced delusions during admission (Vasukevkis, Morandi, Boehm et al. 2011), which, in some cases proves traumatic (Storli, Lindseth and Asplund 2007). Moreover, many have little or no recollection of their time in the ICU. Alternatively, their recollection is fractioned and interchanged with delusions and dreams—indeed, patienthood in the ICU can be a frightening and confusing experience.

What kind of life?

Modern biomedicine has brought about the paradoxical condition labeled by Frank (1995) as "embodied paranoia." Becoming a *victim of medicine*, Frank writes, is a recurring theme in illness stories" (1995: 172). Most often, the fear is of physicians being pushers of a bureaucratic administrative system that colonizes the body and victimizes the patient. Embodied paranoia is the fear of institutions that are designed to help, and is therefore more complex than the fear of disease or bodily decrepitude itself, Frank argues. "The inner conflicts of this reflective paranoia are evident in the troubling analogy between torture and medical treatment" (1995: 172). The patient cannot legitimately hate his or her caretakers because they are only trying to help. Yet at the same time, he or she cannot feel that their efforts merit pure gratitude. As such, the relationship is deeply and troublingly ambivalent. The patients know that they need their caretakers, and technological biomedicine stands out not as an option among many, but as the only viable choice. Nevertheless, the feeling of being a victim of violence remains.

A recent development in the field of intensive care is a greater attention being directed at recovery after ICU treatment. This is due, not only to increasing rates of survival, but also to more evidence of sequelae. Many experienced intensive care professionals explain that their patients are older and more severely ill than the average patient was, 15 or 20 years ago. It is also well known and generally acknowledged among intensive care professionals that the field in several ways (re)*produces* intensive care patients. The very treatments that palliate organic and systemic failures are in themselves not without risk. When the body's functions are overtaken by medical and technological means, they stop working by themselves. Intubation may lead to infections as well as weakened lung capacity. Prolonged immobilization can cause bedsores as well as muscle atrophy. Moreover, research reveals a host of problems both neuro-psychological—depression, anxiety, post-traumatic stress, memory loss and delirium—and physical; muscle weakness, reduced mobility, numbness, taste changes, sleep disturbances and breathlessness (Egerod et al. 2013: 104). Such important sequelae influence a person's social functioning and quality of life. This shows that intensive care treatment is not in itself without problems, even in cases where it is successful. Intensive care technologies have also enabled different modes of survivals that challenge our conception of living itself; the most notable being coma, (persistent) vegetative state (PVS), locked in syndrome, and other states of prolonged machine dependency.

Re-conceptualized dying

> "We should, first, abandon the ancient sign of death—the cessation of the heartbeat" (Henry Beecher, the Harvard ad Hoc Committee, in Wijdick 2011: 3)

These same technologies are thought to have brought about a "reconfiguration of death" (St. Arnaude 1996) or a "new dying" (Locke 2002). Indeed, it was the intensive care technology of artificial ventilation that allowed for the elaboration of new criterions of death, first by shifting the criterion of death from the traditional cessation of breath, to a cessation of heartbeat, and then finally, a cessation of brain activity. The Harvard ad Hoc committee established the first criterion of encephalic death; brain death, after the French physicians Mollaret and Goulon had identified this as "coma dépassée" in 1959 (Wijdik 2011: 3-4). On the one hand, this lends further support to the idea that the person is essentially located in the mind (e.g. Locke 2001). Simultaneously however, it represents a version of dualism in which the mind/body dichotomy is disenchanted, as the mind becomes equated with the organ of the brain. In brain death, death becomes a matter of expertise.

Brain death also escapes common sense as a totally disenchanted view of the human body is not empirically tenable. This is illustrated by the many reactions and aversions created by the prospect of encephalic death, and even more so by the related practice of organ harvest. If the dead human body held no significance other than as "matter", organ harvest and transplantation should hardly provoke either discomfort or reticence. The fact that it has, however, stands as evidence of the fact that even in the West, the body/mind, nature/culture dichotomy has never been absolute, and that people most certainly identify with their bodies—even the insides. As Hennette-Vauchez and Nowenstein argue, brain death illustrates both the result of intensive care medical advances and its limits (2009: 40, 56).

The good death debate

In the language of the law, there is a clear distinction between natural death and its opposite, typically named unnatural, violent, or wrongful death. In brief, a natural death is one that is not caused, willingly or accidentally, either by an external agent or by the individual herself, thus excluding murder, suicide, and accidents. As such, a natural death is a death caused by the organism itself (Debout and Cettour 2006: 66). In contemporary Western ideals of natural death however, it is not this which is at stake, but rather the way in which death is *handled* and the circumstances surrounding it. As Seymour (1999) makes clear, it is the *process of dying* as opposed to the moment of death itself that is the key determinant of the manner in which death is viewed, and the word natural is associated not with biological processes but with a normative claim. Furthermore, an image of a lost, to be recovered natural death has shaped the ‘good death’ discourse in which medical and natural are assumed mutually exclusive polar opposites. Settings such as intensive care are indeed held up as extreme examples of the metamorphosis of death from ‘natural’ into ‘unnatural’ events (Seymour 1999: 691-692).

A telling example of this is the gradual change in the United States of the traditional DNR order—do not resuscitate. Today, DNR has in many places been replaced with the new AND; allow natural death. According to Levin and Coyle’s findings, natural death is associated with open conversation, a personalized, warm, and beneficial approach, healing and an anticipated mourning where no one is responsible for the death. Contrary to this, unnatural death implies a death which is artificially postponed, a lack of open conversation, a medicalized, depersonalized and colder approach, possible moral distress, and delayed acceptance of death as well as someone possibly being responsible (Levin and Coyle 2015: 386 table 1).

Death with dignity

The film “This is where I leave you” (2014), begins with the death of the father of the family. His wife stands in the hospital room, while her daughter calls her other siblings to tell them that their father has passed away. In the background we see the father’s dead body in the hospital bed, with a disconnected tracheal tube still inserted in his throat. During the scene, the recent widowed woman becomes hysterical, and screams that they need to take out the tube. “Let the man have his dignity!” she shouts, violently ripping the tube out of her dead husband’s throat.

The concept of dignity has a longstanding history in the West, yet its meaning has varied greatly throughout the times (e.g., Rosen 2012). In the wake of WWII and during the first draft of the Universal Human Rights Declaration, a consensus was reached stating that all human beings are considered bearers of an ontological dignity, that is, as possessing dignity by virtue of being human. According to Foster, this conceptualization of dignity is the mainstream view *especially* in European bioethics, heavily influenced by Judeo-Christian ideals (Foster 2011: 41).

To the public, however, the death with dignity rhetoric might be most visible in the various interest organizations associated with or campaigning for the legalization of euthanasia and physician assisted suicide (PAS). Nevertheless, also contemporary ethical and legal documents concerning the welfare of patients and patients’ rights emphasize the importance of dignity, in most cases without supporting either PAS or euthanasia. Indeed, patient dignity is a key ideal in medical ethics and the ethics of care in general, not least in the palliative movement. According to the European commission’s declaration on health, “the artificial prolongation of the existence of the terminally ill and dying, by way of medical means that are disproportionate to the patient’s condition, today constitutes a threat to the fundamental rights of all incurably ill patients and to the human dignity of all dying patients” (1999).

The necessity of non-treatment decisions

Due to the potency of intensive care and resuscitation technologies, in many cases treatment reaches an impasse where the patient neither improves nor dies, and further treatment is considered pointless and non-beneficial to the patient. Consequently, a high percentage of deaths in the ICU follow from a decision either to withhold or to withdraw treatment, so-called non-treatment decisions (NTDs). Depending on the source material, anywhere between 25% and 75% of all deaths are of this kind (Klepstad & Gisvold 2003, Domingo, Badia, et. al 2014).

To withhold treatment means to refrain from administering or initiating further treatment measures. For instance, a decision can be made not to initiate dialysis should a patient's kidneys malfunction, or it can be not to administer a new round of chemotherapy. By contrast, when treatment is withdrawn, this indicates an active removal of treatments that are already in place. For instance, in keeping with the aforementioned example, this could mean shutting down dialysis, or turning off artificial ventilation (what is colloquially known as 'pulling the plug'). It should be made clear however, that NTDs, withholding and withdrawing treatment never apply to palliative treatment and care. Thus even in cases where expressions are used such as witdrawing treatment, pulling the plug, DNR (do not resuscitate), this applies only to curative and life prolonging/sustaining treatments. Pain management and symptom control, so-called comfort care, is never forgone, and may even – as we shall see later, be intensified in situations of an NTD.

Although both withholding and withdrawing treatment are considered equal to the law and in medical ethics, and neither option is seen as causing death in either Norwegian, French, and Spanish law, such decisions and the practices of carrying them out, remain contested. Indeed, the sheer number of articles produced by social scientists, researchers in nursing science, medicine, and bioethics, is a testimony to the perceived difficulties brought about by these processes. There are regional, cultural, and religious differences in NTD practices throughout Europe (Førde and Aasland 2014; Romain and Sprung 2014; Sprung et al. 2007). In some places, NTDs are highly formalized events, and in other places decisions are made informally by the physician in charge of the patient in question.

Some see deaths following non-treatment decisions as being per definition unnatural (Kentish-Barnes 2007), reducing what ought to be a ritually dense transition to a decomposed decision or even a technical phenomenon (Ariès 1975). Kaufman has voiced the concern that medical technology could contribute to, or even create "bizarre and unnatural forms of human life", where "death could become *a matter of deciding when a person should die and when a* *person should be considered dead*" (Kaufman 2005: 65). Conversely, the absence of NTDs is no less contentious, as the alternative, many fear, is excessive treatment. As Frank has written, it is a very common thing to hear, that people do not want to "die on a machine" (1995: 172).

Authors have argued that technological achievements in medicine may be regarded as a threat to the individual's "freedom to die" (Hewa 1994: abstract), or even caution that "scientifically orchestrated death might come to replace the authentically human death" (Dupont 2007: 69).[3] It is important to note however, as Kaufman does, that death is not in fact, a natural phenomenon. Rather, she argues, death is "shaped, known, defined, and disputed through the varied forms of human activity that surround it" (2005: 62). Moreover, in the words of Green: "like birth and marriage, death is ritually dense in all cultures" (2008: 31). In practice, this means that intensive care personnel have to balance a fine line between the ideology of rescue, which lies at the heart of their practice, and a recognition that rescue attempts sometimes do more harm than good, which forces existential decision-making and dealing with end-of-life issues in a setting commonly understood as suboptimal. Once more, the scapegoat receiving the blame for indignity is technology (Seymour 1999, 2000).

An artificial split? Technology versus Care

As will have become clear by now, technological expertise is one of the characteristics of working in intensive care. Yet this is not without its problems. Indeed, nursing, more so than medicine, has traditionally been regarded as a profession within healthcare that is primarily concerned with ensuring patient comfort and support—*care*. Those concerned with the human, with the spiritual or cultural aspects of care, oftentimes take issue with technology as an antagonizing and inherently alienating force (Girard 1988). Working with technology, therefore, is oftentimes perceived as an outright danger to the essence of the profession, described as an *agent* in the clinic with a *looming presence* that *conditions* the caregiver's vision, and *shackles* action. Consider the following phrase: "Technology, with its exciting captive lure and challenging character, seduces the caregiver and lulls them into a fictive sense of security and safety" (Almerud et al 2007: 132). Zussman concluded in his ethnography of North American

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[3] La mort mise en scène scientifiquement entend se substituer au mourir authentiquement humain.

intensive care in the late 1980s that both nurses and physicians had in fact become technicians (1992: 80).

Researchers in nursing science have shown how technology may indeed overshadow the patient in the care-encounter, be time consuming, and draw attention from other aspects of work. A Swedish study of the meaning of technology in the ICU, conducted by Wikström, Cederborg, and Johanson (2007), showed that nurses perceived the technology with which they worked as being both decisive and facilitating. As such, it was something that directed and controlled the treatment of the patients, but which also led to their wellbeing, making the treatment more secure, and decreasing the caretaker's workload. Yet, they also found that it was a complicating factor in work, because it was difficult to handle, not entirely trustworthy, and at the center of ethical conflicts. These are recurring themes. The pervasiveness of technology in nursing, results in a paradoxical neglect of the patients, who despite being monitored and observed ostensibly and constantly, are not really *seen* (Almerud, Alapack et al. 2007).

This is part of the dehumanizing effects of technology in action; the patient's body becomes a range of organs, pieces, systems portrayed through technological and calculable means such as monitors and test results. Indeed, as Almerud et al. report, "The faith that caring personnel demonstrate in apparatuses is not matched by comparable reflection upon their dominant presence and impact at the human level" (2007: 155), or "technical tasks take precedence over and seemingly are more urgent than showing care" (2008: 56).

Caring for machines, or caring for a patient?

For newcomers or inexperienced nurses, the many and complex pieces of equipment require much attention, "babysitting" and constant monitoring (Almerud 2007, Alasad 2002, Wikström et al. 2007, Price 2013). There is however also a more nuanced side to this. As Price (2013) notes, it is difficult to separate the caring and the technological elements from other cultural influences, and they are often intertwined. Alasad (2002) refutes the idea that the ICU nurse is primarily a technical agent and describes technological caring as an "ethical process" (2002: 407). Although machines and technical tasks are time consuming, especially for novice nurses, as a nurse gains experience and confidence, Alasad writes, technical tasks appear more manageable, less time-consuming and shape the interaction with and the approach to the patient to a much lesser extent (2002). Thus the studies typically conclude that technology and care are intertwined, and that there is little evidence to suggest that they cannot coexsist Wikström et al. 2007; Almerd et al. 2007)..

What we see however, is a back and forth between technological determinism on the one hand, according to which technology may take on a life of its own and become the master of humankind. On the other hand, the constructivist view portrays technology as consisting of tools that may be used for good or bad, the value of which depending upon the use and power wielded by the humans who devise and employ it. Nevertheless, the worry remains that technology will drown out the voice of the patient and render unimportant that which cannot be measured or calculated.

Part 2. Methods, theories, and ethics

I now turn my attention to the actual execution of the project itself. My doctoral project was always intended to cross disciplinary boundaries. Indeed, *interdisciplinarity* has become something of a buzzword over the last decades and projects combining different disciplines or sub-fields are often thought to be of particular relevance. Nevertheless, there are risks associated with such work—not being accepted by either discipline or not fitting in. Consequently, working interdisciplinarily brings with it at times troublesome issues of legitimacy. Cerwonka details this in her book chapter fittingly named "*Nervous condition*" (2007). Already in its earliest conceptions, I intended this project to work across disciplinary lines. It was also in part due to this project design that I chose to write an article-based thesis. My academic background is in philosophy.

Throughout the project, methods, theoretical standpoints, and ethics have been continuously intertwined entities. In the following section, I discuss the choice of field sites and ethnographic methods. I also account for the theoretical frameworks and approaches that have been central to my approach in the field, as well as the interpretation of data. In addition to the empirical, ethnographic approach, a critical utilization of philosophical theories, such as actor-network theory and Mol's conceptualization of enactment, phenomenology, and microethics have been important parts of the project.

This part also deals with ethics. In fact, more than anything else, ethics has been the recurring word throughout my work. Not only were ethical concerns part of my research objectives. Conducting empirical studies in a clinical setting also requires formal ethical committee clearance beforehand. The terms of this clearance played an important role in creating a framework and demarcating the boundaries of the actual empirical work. Moreover, during the course of fieldwork, the ethics of such embodied observation and the moral-ethical quandaries to which this project gave rise became of the utmost importance. I came to experience the need for, as well as a fascination with, what I call the ethics of observation, with which I also deal in this section.

The field sites

> Intensive care is a space of tensions, where one cannot keep anything to oneself; not the patients, or the caretakers, not even the observer. Conducting research in this environment pushes one to the limit. (Bergé 2006: 9. My translation)

I conducted fieldwork in three hospitals situated in three European countries; my native Norway, France, and Spain. The reasons for choosing these three countries were in part pragmatic. In order to observe in the unit, it was vital to be able to understand conversation—not only when the personell was talking to me, but also when they were addressing the patients and their colleagues. It was also a great advantage to be able to interpret body language and gestures, at least to a certain degree. Consequently, the settings for conducting fieldwork diminished naturally to include only countries or places where I could speak and understand the working language, and would not have to rely upon translators or the personnel addressing me in a different language than their working one. In addition to being Norwegian myself, I have experience living and staying for extended periods in both France and Spain, and thus felt somewhat familiar with the cultures. Moreover, I was quite intrigued with the prospect of doing a sort of European study; indeed, looking at a map, the tree countries are located on a curbed string going from the outermost north of Europe, to the very south.

All three units were adult, multipurpose units, situated in urban university teaching hospitals. The units each had a capacity of approximately 10 to 16 patients at any given time. The qualifier approximately is necessary because in all three units there were rooms that the managers preferred not to use, but that might nevertheless be employed if the need was great enough. In the units, I employed an approach of participant observation—although the participant element is necessarily limited in this type of context. I shadowed personnel in their regular activities, observed during rounds, staff meetings, meetings with next of kin, treatment and care of patients, and participated at lunch and breaks. Moreover, I conducted 24 semi-structured interviews with members of staff, nine physicians, 12 nurses and three nurse's aides. For the sake of anonymity, I have renamed the hospitals according to their geographical location relative to one another. Thus, Hospital North is the one in Norway, Central Hospital in France, and Hospital South is the hospital in Spain. For the sake of clarity, these pseudonyms say nothing about the location of each hospital within the relevant country.

Interviews

Interviews were semi-structured, and lasted anywhere from 20 to 45 minutes, depending on the person I was interviewing. The questions were detailed in an interview guide, which was accepted by the Regional Committee for Ethics in Medical and Health Research (REK).

I asked each person how long they had been in their current profession, and why they had chosen intensive care. Thereafter, I asked what treating the patient meant to them, and if there were stages in an admission in which to treat (*å behandle* (No.), *traiter* (Fr.), *tratar* (Es.)) the patient took on different meanings. I inquired into the notion of dignity, and asked the respondent to elaborate on their understanding of the concept, and on what they did in their daily professional activities in order to respect or to promote patient dignity, and whether there were times during an admission in which dignity became increasingly or less important. I asked how they felt about experiencing deaths in the unit, and if there were any circumstances or types of death that they felt more or less comfortable with. Lastly, all respondents were asked about their opinion of the next of kin's role and presence in the unit.

When communication was flowing, the respondent him or herself would largely decide the direction of the interview. Other times, I had to interject supplemental questions in order to edge the conversation along.

All interviews were voluntary, and I received either written or oral consent. Respondents were sometimes appointed to me by the management staff in the unit, some volunteered, and other times I simply asked a random personnel member. The interviews were recorded with the permission of the interviewee, and I later transcribed them.

A note on languages and translation

Whilst conducting the research, I operated in the language of the particular unit, and all conversations as well as the interviews were conducted in the local language. The Spanish unit was a bit different, as approximately half of the personnel had Catalan as their first language. However, I had no difficulties understanding simple conversation and medical jargon in Catalan. The interviews were conducted in Castilian Spanish, but this did not pose a problem, as all the Catalan members of staff were bilingual.

Later, when employing the obtained materials from the field in the articles, I had to translate these into English. With regard to the interviews, I have attempted to stay as close to verbatim translation as possible. Concerning my rendition of informal conversations, I have relayed these to the best of my memory, although these are not presented as, and should not be read as direct quotes. Especially informal speech, metaphors and idioms resist direct translation, as does the body language and gesticulations that oftentimes accompany it. All translation involves compromise, and, as Redfield writes, at times verbatim rendition has to give way to a translation that better conveyed the intended sense (Redfield 2013: 4).

Doing ethnography – partiality and positionality

To quote one of anthropology's classical authors, Malinowsky, ethnographic research aims to grasp "the native's point of view, his relation to life, to realize his vision of his world" (Malinowski 1922: 25). This description bases itself on three main sources; what people *say*, what they *do,* and the objects that they use. Ways of obtaining such data are many, yet, the practice of participant observation remains a most central ideal in ethnographic research. Participant observation predicates that the researcher enters her field, not as a so-called "mere observer" but that she participates in the activities, conversations, and lifestyle of the informants in the field. In doing so, it is believed that she will gain access to a more real, profound understanding of her field of study. In his classic "*The Presentation of self in daily life*" (1959), Goffman differentiated between what he called the front- and backstage of social life. Front stage, in Goffman's sociology is what we reveal to the outside, our outward behavior and image. Backstage, however, is reserved for the privileged insiders, and is thus more real and profound. On a certain level, I believe Goffman to be correct. It seems intuitively true that we share different things with outsiders than with those closer to us. This is in part what makes entering any new social setting so difficult: there is a level of testing, a liminal phase where the newcomer must prove her worth, and her value to the group, in order to be included. This is challenging in any setting, and it is generally accepted that to conduct participant observation is to situate oneself in a space of tensions, continuously balancing detachment and engagement, proximity and distance, empathy, and critique. Writing about ethnography, Hastrup states that there is no way of seeing from nowhere in particular (Hastrup 1995: 4), by which two things are implied. First, ethnographic knowledge is always situated, and secondly, it is never "objective" in the sense intended by the natural sciences. Indeed, Clifford concurs: "ethnographic truth is (…) inherently *partial*—committed and incomplete" (1986: 7). The ethnographer is a positioned subject, and this means that some ethnographers will necessarily grasp certain phenomena better than others. This is influenced by a range of things, including gender, outsider status, and age, not to mention the researcher's own life experiences (Hastrup 1992: 119). It is not however, a problematic element of anthropology. In fact, Hastrup states, "knowledge is so self-evidently partial that the label is meaningless" (1995: 59). Understanding in her opinion, is an imaginative event that implies human agency. Meaning is not given or preexisting.

Writing ethnographic research therefore demands a recognition on the part of the researcher of both this partiality and positionality. As will become even more clear in light of Mol's praxiographic approach to which I will turn in a bit, I believe Emerson, Fretz, and Shaw to be correct when they write that "an account of reality does not simply mirror reality but rather creates or constitutes as real in the first place whatever it describes" (1995: 213). More specifically, I am inspired by the autoethnographic approach to doing and writing ethnography.

Autoethnography

Autoethnography refers to research, writing, and method within ethnography that connects the autobiographical and personal, to the cultural, social, and political. Here, the researcher speaks with a clearly audible voice and her personal experiences in the field become a conscious and intentional part of what is studied (Ellis 2008: 49). There are several ways of doing this, but it often involves highlighting private details of emotional and bodily experience in order to draw attention to both the particularities of a case as well as what this may contain of general interest (Ellis 2008: 50). Authors may single out "epiphanies" or specifically powerful moments during research, set to reveal ways in which one might negotiate intense situations, images, feelings or lingering effects of experience (Ellis, Adams and Bochner 2011: 6). Autoethnography has become more influential in anthropology over the last two decades. As such, it is a blurred genre that brings together the social sciences and the humanities (Ellis 2008: 49-51).

I am partial to this format and procedure, in part because it coincides well with the way in which I conducted my fieldwork; that is, by constantly writing, both descriptions of the field, transcriptions of dialogue and the like, but also my own experience. My data collection and analysis proceeded simultaneously (2011: 20). Therefore, I have used vignettes, reflexivity, and introspection, not for the purpose of self-indulgence, but in the hopes of offering lessons, as Ellis writes, for further conversation and to illuminate the culture under study.

Observing hospital units The participant aspect of observation in work-place ethnography is oftentimes limited, due to the degree of specificity and professionalism required for the tasks performed at the site. When the field site is a hospital unit this poses an additional set of challenges. The clinic is highly structured and governed by rules and regulations—not least pertaining to the protection of vulnerable patients. Only select categories of people frequent clinics, and the ethnographer's presence adds another category of person into the space, whose status does not fit into any other, as also Kaufman noted in her monograph on death in North American hospitals (2005).

As I was fortunate enough to visit different sites, I was able to experience the problems, dilemmas, and fascinating situations that conducting ethnographic fieldwork in a clinical setting may present in three different places. There were clear points of commonality: the awkwardness of knowing where to stand so as not to be in the way, finding out whom to ask for what, where it was better to have lunch, with whom one should ally, and discovering where the limits of one's welcome and goodwill on behalf of the personnel begin and end. On the other hand, despite the similarities of these highly standardized sites, my role in each place and, accordingly, my overall experience varied greatly between the three clinics. This did indeed influence the type of ethnography I conducted at each site, as well as the character of my observation. I shall look at this more closely in a bit. First, however, I will elaborate on some of the central theoretical frameworks that cultured my approach to the field, and the interpretation of data.

Technology-in-practiceAs should have become clear in the previous section, the (omni) presence of technology and the tension it provokes makes an investigation of technology necessary for any inquiry of "ethical and existential issues" in intensive care. Looking at cultural experiences in medicine, one cannot ignore either the physical or technology. The literature often reflects either a stance of technological determinism or social constructivism. By doing so, Timmermans and Berg point out traditional writings in medical sociology have either overestimated the power of technology to change society, or underestimated its role (Timmermans and Berg 2003: 103). Yet technology does not only generate value questions, it is also related to values as such (Hofmann 2001: 335)—that is, values influence the very existence and development of different technologies. Rather than chose between either constructivism or determinism, then, I have leaned on Timmermans and Berg's work, as they have argued the need for a comprehensive view of technology. This approach, they say, is less romantic than that of both determinists and essentialists, because it includes smaller and less exotic elements. Rather, it involves looking at technologies in the plural, including

> the entire gamut of mundane to sophisticated technologies, drugs, and even managerial instruments such as patient records. Actually, in this approach it is difficult to single out one technology as an isolated device because technologies are embedded in relations of other tools, practices, groups, professionals, and patients and it is through their location in these heterogeneous networks that treatment, or any other action, is possible in health care. (2003: 104)

A focus in my empirical investigation therefore, has been to look at technology in practice. How did it function in concrete empirical contexts? I chose to draw upon the current of Actor-Network

Theory (ANT), and more specifically Annemarie Mol's praxiographic approach, and focus on *enactment.*

Actor-network theory

Actor-network theory (ANT) was introduced by Latour. According to Latour, the modern world view is fundamentally paradoxical, as our paradigm values clear cut separations between entities and classes—such as nature and culture, human and non-human, whereas our activities, not least scientific, are constantly producing more things that are hybrids, a mix of categories that do not fit in to either one completely. Hybrids, say Latour, problematize our line of thought and our logic (1991). Anthropologist Law explains; "It isn't simply that we eat, find shelter in our houses and produce objects with machines. It is also that almost all of our interactions with other people are mediated through objects" (1992: 381). Machines, architecture, clothes, texts—all contribute to the patterning of the social. According to ANT, both humans and objects may have active agency. This means that there is a political side to artifacts, and the dividing line between people and machines is subject to negotiation and instability. Humans can take on the attributes of machines and animals, as much as machines and animals can gain attributes of humans such as intelligence and responsibility (1992: 383). Analytically, therefore, proponents of ANT state that what counts as a person, for instance, is an effect generated by a network of heterogeneous, interacting materials. Whether humans or inert objects hold the determining power in a particular context, can only be determined empirically. Thus to view technology as an actor, is neither saying that it is stronger than humans are, nor that it is necessarily alienating.

The Field multiplies

In her book "*The body multiple: Ontology in medical practice*," (2002), Mol describes and analyses the disease *arteriosclerosis* in a Dutch hospital. Mol argues that medical anthropology and sociology have concerned themselves mainly with accounting for the human-social aspects of medicine, leaving its assumptions about nature largely untouched (2002: 9). She employs what she calls a "praxiographic" approach, combining empirics and philosophy, drawing upon the same framework as ANT. Praxiography refers to an un-bracketing of practices and describes how objects are made present in the complex practice within which they are constituted (Hadders 2008: 18). According to Mol, “no object, no body, no disease, is singular. If it is not removed from the practices that sustain it, reality is multiple.” (2002:6). One should therefore speak of *ontologies* in the plural, and these are “brought into being, sustained, or allowed flourish in day-to-day, socio-material practices” (2002:6). By using “enactment,” the world as we know it, comes into being through action, and this is the result of an intricate network including people, artifacts, and technology. “In practice” she writes, “the body and its diseases are more than one, but this does not mean that they are fragmented into being many.” (2002: preface viii).

By employing enactment rather than construction, Mol transforms what could have been merely an analytical point into an ontological issue. Indeed, according to Mol, what exists is not given in the order of things. It is not a problem of how to arrive at correct knowledge, so much as an issue of different and multiple ontologies. For some, I suspect that this can be a hard pill to swallow. Moreover, Mol’s approach and theories have received some criticism for paying too little attention to humans, and putting too much emphasis on objects (Hadders 2008). Nevertheless, I believe that her approach can be accepted as an analytical framework, even without accepting the ontological argument. Conceptually blurring the line between subject and object, between *actant* and *acted upon*, is useful in a setting where a blurring of categorical lines consistently and persistently takes place empirically. Furthermore, an important conclusion drawn from Mol’s approach is that technicalities— administrative routines, techniques, and materials—are all value laden and ideologically informed; contingent and dependent upon traditions, power plays, and coincidence. This makes them open to contestation (Mol 2002:171).

Drawing from ANT and Mol facilitates a comprehensive view of technologies, allowing importance also to those that are unimpressive, such as record keeping. This aided me as an ethnographer to approach the machinery and the human-machine patients of the ICU without the prejudice that this was necessarily alienating or negative—a tendency that, as we have seen, is pervasive in much of the literature. Moreover, Annemarie Mol’s praxiographic approach and theory of enactment, according to which any given reality is continuously in the making and unmaking, made me aware of my own presence as a researcher in an engaged way. As mentioned, observing in the clinics consisted of a lot of standing and attentively *looking, smelling,* and *listening,* as well as following the staff around in their work tasks and meetings, both between colleagues, and sometimes with next of kin during which I did not actively participate. Nevertheless, moving around the clinic, the observer does more than subject the space to a detached, scientific gaze. This leads to the next sequence: phenomenology.

Phenomenology

> For ethnographers, embodiment is more than the realization that our bodily experience gives metaphorical meaning to our experience; it is rather the realization that (…) we too are consumed by the sensual world, that ethnographic things capture us through our bodies, that profound lessons are learned when sharp pains streak up our legs in the middle of the night. (Stoller, 1997: 23)

In a phrase, phenomenology can be explained as the study of things as they appear, introduced by German philosophers Edmund Husserl and later Martin Heidegger. In anthropology, this approach has been especially popular within the domain of health and medicine. It has been a central element to my approach in the field, in particular the philosophies of Maurice Merleau-Ponty and Emanuel Levinas.

Phenomenology highlights the importance of the description of things (phenomena) as they are experienced, at the same time as it puts emphasis on the creative role of the observer, in this case the ethnographer. Description is neither a view from nowhere nor a view from everywhere, but always a view from *somewhere*. According to Emanuel Levinas, *looking* is a fundamentally incarnated activity. There is an intricacy of viewing, Levinas says, that often goes unnoticed in everyday practice, namely the relationship (and perhaps I would say tension) between that which is seen presenting itself and assembling a multitude of characters allowing it to be perceived, and the viewing in itself as an actively constructing activity. As such, to perceive includes both impression and expression, of input and output (Levinas 1972: 28).Phenomenology is therefore not removed from the greater context. It should be seen as an attempt to describe lived space, lived time and lived worlds (Merleau-Ponty 2012: 7); as a rendition of culturally embodied experience. The pure quale—Kant's *Ding an Sich*—would only be given to us, said Merleau-Ponty, "if the world were a spectacle and one's own body a mechanism with which an impartial mind could become acquainted" (2012: 78). For example, seeing a wheel lying on the ground is not the same as perceiving a wheel carrying a cart, the sight of a hand is not the same as the sight of a hand that just slapped you in the face. Simply put, the same phenomena do not produce the same conclusions or the same connotations regardless of the situation and regardless of the viewer.

Sensing always involves a reference to the sensing body, as Merleau-Ponty explains. Influential phenomenologist anthropologists such as Thomas Csordas and Michael Jackson push to posit the body as the ground of culture. They argue that to subjugate the bodily to the semantic is not empirically tenable. Csordas therefore claims that the body is not an object of culture or something to be studied as such. It is the *subject* of culture, and its existential ground. The body is in the world already (déjà-là), and is therefore prior to all other meanings (1993: 135-138) Posture here becomes a way to negotiate with an objectively existing outer world with which there are multiple possible ways of engaging.

Phenomenology and ethics

Levinas locates what he considers to be a pre-cultural origin of ethics in the encounter between two human beings. To be faced with the other, Levinas says is to be faced with a radical otherness that solicits and demands our attention. Indeed, his philosophy places a special emphasis on precisely *the face of the other*. We are responsible in front of our fellow human. This is revealed linguistically in the French language where the word to "see" or "look" and "concern" may both be expressed by the same word "regard." Indeed, to see another is to enter into a relationship with them, and to gain access. As anthropologist Le Breton makes explicit; there is a tactile dimension to seeing, which transforms it into either a weapon or a caress, according to the circumstance, as it aims at the most intimate and most vulnerable aspects of human beings. It may even be an act of asserting power over the one who is observed (2004: 252-253, 258). According to such a view, the embodied experience of witnessing, of being faced-with puts the observer in a relationship with the observed that is all but distant, neutral or outside of the realms of ethics. Certainly, the observer can look back upon a situation and explore new interpretations or meanings of a given situation. However, there is also a certain representation of the incoming quale being created on site.

Senses of observation

Classen has argued that the sensory anthropologist attends to the role of odors, tastes, and *tactilities* as "essential clues to the ways by which a society fashions and embodies a meaningful world" (1997: 405). In the clinic, a vital part of the surroundings is olfactory. Interestingly, I noted, in all three clinics the smell was somehow the same. This particular hospital smell, representing in my opinion, the simultaneously hygienic need and aesthetic desire to erase the odors of illness; of bodily fluids, medications; of sickness, contagion, and ultimately death itself, by use of odorless substances such as unperfumed soap and anti-bacterial fluids. Another key element is noise or the absence of such. The ICU in Hospital North was pervasively and all-encompassingly silent. This made for an almost sacral feeling, and oriented the way one moved throughout the site, a liminal space, a vacuum, existing outside of time and space. In Central Hospital, the contrary was the case, and my field notes are filled with references to noise, alarms, chatting, and shouting. Other times, my ear caught the whistling of one of the aides, humming "don't worry, be happy" as he transferred medical equipment around, or the lyrics of a song playing softly over the radio. I wondered if anybody else noticed the bitter irony of John Legend singing about how his head was under water, yet he was "breathing fine," while the respirators wheezily chimed in, making for a rather morbid chorus. Furthermore, tactility comes into play for the observer by virtue of its absence. Being forbidden to touch anything, having nowhere to place one's hands, and always being in the way, provokes a certain awkward embodiment. So does the constant feeling of dry skin on one's hands that comes from repeated use of alcoholic solvent. Before entering a room, before touching, after touching, before leaving, the sticky alcoholic liquid is rubbed thoroughly on the hands, between each finger, over the wrists. Even without performing any chores, the observer joins in in this ritualized activity: as the dirt of the world must be cleansed before approaching the sick, so too must the dirt of the sick be washed away before reentering the world.

In the Nordic winter when the heat appeared to be off, I was cold together with the nurses in my short sleeved, oversized scrubs. And I tugged at the fabric sticking to the back of my thighs from sweat, when spring came early on the continent, and the air-conditioning was broken. Even as a mere observer, I did not only see my field, I smelled it, and touched it, tasted it, and listened to it. All of which translated in my opinion, to ultimately *feeling* the field, giving rise to affective and emotional reactions, drawing upon the idea of sensuous scholarship as coined by Paul Stoller (1997). Despite the clinical ethnographer's admittedly detached role in the clinic, such observation too is at its very core, embodied. Bodily or emotional experiences are not nuisances to be overcome or irrational aspects lessening the value of scientific work. There is a need for paying attention with the body (Csordas 1993: 138), also in less participant forms of ethnographic work.

The view from somewhere, and the access accordingly

> So, you're an anthropologist? What's that? Oh, like Bones! Cool. We'll call you Bones, then.[4]

The overall attitude expressed toward my work varied in all three locations. The different ways of regarding my position in the unit, and where it was most "natural" for me to conduct most observations, as well as the level of inclusion, made for different approaches on my part. In some places, it seemed most pertinent to make myself as invisible as possible, in other settings I could partake as a member of the team.

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[4] This is a reference to an American forensic crime-drama series, also broadcasted in Europe, where one of the main characters is a forensic anthropologist who works with human remains, and whose nickname, "Bones" is also the title of the show.

ICU North was the first unit that I visited, and it was the one where I had spent three weeks two years earlier in connection with my Master thesis. As such, I thought I would have an advantage, being a returning feature. It was decided that my place was with the nurses. The choice seemed obvious, and it was said that this would be more fitting for my inquiry, not least because the nurses spend all day with the patients and as such are closer to the action. My access to medical staff was limited. An information form had been prepared ahead of my stay for both nursing staff and medical staff. However, the head nurse and head physician both expressed that staff would probably not read it because people tended not to read their emails. Yet that way, no one could complain because technically, information had been provided. At the end of my first week, the head physician approached me, admitting, amused, that in fact, he had forgotten to distribute the information. This, I thought, explained why none of the physicians seemed to understand who I was or what I was doing there.

Several nurses seemed uncomfortable with my presence; one refused to have me present in the patient's room despite a direct request made by the head nurse, as the situation was particularly pertinent to my research. Others made skeptical remarks about my field of study in comments such as "Well, you can just study anything at all these days, can't you." On one occasion an administrative nurse was charged with the task of finding suitable subjects for my interviews, yet when asking a group of nurses sitting around having nothing to do (as does happen, even in the ICU), they all refused. During lunch break, I would mostly sit by myself and so did several of the nurses. If a group were having coffee, they would present as a united front of which I was very much not a part. A few volunteered to talk with me and to be interviewed, and some nurses in particular were very generous with their explanations and descriptions. The difference in attitudes, nevertheless, was palpable in both Hospitals Central and South.

Arriving at Central hospital in France, nothing seemed to be clear, and I quickly went into silent "worst case scenario" mode. The doctor who had authorized my stay was absent, and during the first few minutes, complete confusion reigned. However, one senior doctor suddenly remembered having "read something about it"—as I had sent an information form to this hospital as well. Subsequently, and much to my surprise, I was instantly accepted into the fold. A senior doctor took me to get some scrubs and prompted me to leave my bags in the interns' wardrobe. Afterward, the doctors interrupted morning rounds to allow me to present myself to the team.

Shortly thereafter, some of the nurse's aides invited me to have coffee with them, and almost on a daily basis, I had lunch in the cafeteria with members of the staff, either physicians or nurses – most often at their expense, as they insisted on paying for my food. That was French hospitality, they insisted, and it felt ruder to refuse than it did to accept.

The fact that I was a foreigner seemed to work to my advantage. On the one hand, and I believe quite importantly, this meant that the chances of me being allied with hospital administration, or working some kind of secret audit, were minimal. The units were going through a transition and this was brought up on some occasions as resentment toward the administration was noticeable. Furthermore, asking about where I was from, my experiences in France, and so forth, created an easy point of access into light topic conversation, and a made for a "neutral territory" icebreaker.

I did not have a formal contact person in Central ICU, but I was instantly included by physicians and intern doctors and accepted as a natural feature in their afternoon meetings. On a regular basis, members of staff asked me if I had everything that I needed, and not to hesitate to ask; the service being, as a resident doctor told me, an "open bar." I also received several appendices and nicknames, which I gladly accepted, as it spoke to a level of comfort with my presence. On occasion, I followed intern staff around, or nursing staff, spending quite a bit of time chatting and just "sitting around" during breaks. This allowed for a significantly more participant angle on the observation. Both the nursing and medical staff at Central hospital was young, which meant I was roughly the same age as many of the nurses and intern physicians. It seems likely that this had a positive impact on my acceptance.

Much the same was the case in hospital South, where most seemed well informed of my presence upon arrival. My person of contact was one of the experienced physicians, who went above and beyond to facilitate my inclusion in the unit, particularly among the doctors. One physician in particular was quite vocal about his skepticism toward my project. It was not, he pointed out, science. In his case, however, this made me such a non-threatening and non-pertinent presence in the unit that he in fact became a very good "informant" as we often engaged in light topic conversation.

This unit was more architecturally divided than the ICUs in Norway and France had been, which made observation somewhat broken up, as it required moving around from place to place. Yet most people seemed comfortable with my presence, and after a while included me in jokes—sometimes at my expense (as it turns out, I was somewhat of a jinx), and offered, like at Central hospital, to come up with a new name for me, as my real name was "too weird." Although less so than in Central hospital, I often had lunch with medical staff, particularly with the intern physicians who were closer to my own age, and spent time chatting with staff in the break room. They readily included me in conversations with next of kin and at rounds. Here, I was also expected to formally introduce my project to the doctors at the beginning of my stay, and gave a short summary of my experiences at the end of the period. It was the last hospital that I visited, and they showed great interest in learning about the differences and similarities between their unit and the two previously visited.

In both hospitals Central and South, it was perceived as natural that I should spend most of my time with the medical staff. Access to rounds and physicians' meetings was a given and contact with nursing and auxiliary staff was in most cases made through a representative of the medical staff. As mentioned, one of the reasons given in Hospital North for limiting inclusion to nursing staff was the fact that nurses spend the most time with the patients, and that it would therefore be more pertinent for my inquiry to spend time with them. On the other hand, although never expressly stated, I also believe it to be an issue of status—both that of nurses and my own. This cannot be confirmed nor denied in the present study, and must therefore be seen as a hypothesis on my part.

Does your father like to fish? Gender in the field

Once, in the Norwegian unit, after having observed as an experienced physician conduct a small one-person procedure, the physician turned to me as he was cleaning the equipment in the sink. "Does your father or brothers fish?" He asked. At first, I did not quite understand his meaning. Nevertheless, I answered that, yes, in fact my father did. The physician then told me that he thought it terribly wasteful to get rid of all that barely used equipment, and that in his experience, it was perfect for fishing (clamping hooks etc.). He already had plenty at home, however. Therefore, he said, if my father and brothers fished, he could give it to me, to give to them.

I doubt that this episode meant much to the physician in question, and I admit I did not think much of it at the time either. Yet it is not without importance, as it does indeed illustrate the subtle ways in which gender plays a part in our research. As nice and generous as this physician's inside offer was, it did not occur to him to ask first—or indeed at all, if *I* liked to fish. Oftentimes, perhaps not least as an academic or a researcher, one tends to forget how one is perceived by the outside world, and that this may not primarily (or indeed at all) be based on our intellectual merits. Reflecting back on the episode of the "fishing equipment" is a useful reminder of the fact that not only does the researcher evaluate the field—the field evaluates and judges her right back.

Hospital clinics are a workplace where the traditional gender division of labor is clear: most nurses are women and most physicians are men. In Hospital North, this was very much the case. Out of almost one hundred nurses, there were no more than seven men on staff. Moreover, out of all the doctors I encountered—approximately 10—only two were women. At both Hospitals Central and South however, the gender ratio of the physicians was closer to 50/50, and particularly at Central hospital, many of the care workers (nurses and nurse's aides) were male. In many respects, I believe that my gender played a positive, albeit utterly undeservingly so, role in my data collection. Indeed, I do believe I was privy to information that I would not have been, had I been a male, precisely because being a blonde, feminine woman, made me seem harmless and non-threatening. Indeed, what could be the harm in letting the *little Norwegian*[5] tag along?

Unit cultures

On the one hand, an important finding in this project is the similarity between the three sites. Having been in one unit, transitioning to another, posed no problems. Despite the different roles I was accorded in each place, the homogenizing effects of scientific medicine in practice are striking. Scrubs are scrubs, hospital shoes are hospital shoes whether they be crocs or ugly

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[5] Little Norwegian was one of my nicknames in Central Hospital; «petite norvégienne». Using the diminutive «little» is a common way in which to refer to someone in an affectionate way in France.

sneakers, the brash movements of doctors is the same, and so are the patients, who appeared interchangeable from one place to the other.

In Norway and Spain, the nursing and medical teams functioned seemingly independent of one another, with limited interaction. The French ICU teams were younger, and put heavy verbalized importance on teamwork, collegiality, and the complimentary roles of the different professional groups in the clinic. A significant difference however, was the extensive use of humor among the caretaker and medical teams in Central Hospital in France. Gallows humor and dark humor are notorious in hospital contexts (Barrett 1994; McCreaddie and Wiggins 2008; Watson 2011; Santos and José 2012; Wear, Aultman, Varley et al. 2006). However, I observed this only to a small degree in Hospital north and Hospital South. In Central Hospital, derogatory, sexualized, and feces-centered humor was a pervasive trait of the unit culture. The Spanish team, on the other hand, was self-conscious of being compared with a Northern European Unit, oftentimes making unsolicited (and unnecessary!) excuses for the noise in the unit and for their self-proclaimed "Latin temperament."

The ethics of research in the clinic

Ethnographic research in any setting carries with it an ethical responsibility. As a researcher, one is granted access into people's lives, and this is not to be taken lightly. Today, most research involving humans is subject to regulations. These may require that ethical committees, organisms handling public records or the like, approve of projects. This applies even more so when the individuals involved are deemed vulnerable, such as institutionalized persons and persons who cannot provide informed consent. Research could constitute considerable infractions upon an individual's freedom, autonomy and privacy. The aim of this section is to reflect upon the moral and ethical quandaries encountered as an observer in the clinic.

What makes clinical ethics ethical?

Emanuel, Wendler, and Grady (2000) have singled out seven items "necessary and sufficient" in order for clinical research to be ethical. 1. It must lead to enhancement of health or knowledge in the field in question, 2. Must abide to standards of scientific validity/methodological rigor, 3. Subject selection must be fair and unbiased, 4. The study must have a favorable risk-benefit ratio, 5. An independent review of the project is to be made, 6. Participants must give informed consent and, finally, 7. There must be respect for enrolled subjects (2000: 2701).

In Norway where my research was based, guidelines for social scientific research is found in the document "Guiding principles for research in the social sciences, the humanities, law and theology,"[6] elaborated by National Research Ethics Committees in 2006 (Kalleberg,Balto, Cappelen, Nagel, Nymoen, Rønning, Salomonsen, Schreiner, Semb, Skjelbred, Askheim and Vandvik 2006). This document is designed to assist researchers in reflecting on "their ethical ideas and attitudes, to become conscious of conflicts of norms, to increase good common sense and the ability to make well-founded choices in cases of contradicting considerations", stating that research ethics is "a codification of practiced scientific morals. It thus has its basis in general scientific morality, just as general ethics has its basis in society's general morals" (2006: 5).

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[6] Forskningsetiske retningslinjer for samfunnsfag, humaniora, juss og teologi. My translation.

According to the National Research Ethics Committees, research involving vulnerable populations is only acceptable if it complies with the following conditions: i. The study cannot be conducted in another way (i.e. without including said population), ii. Research is considered to benefit the (researched) population directly. iii. No significant harm should come to the persons included. Nevertheless, it may be conducted without consent on the condition that the researcher has no physical contact with the subjects, and that these subjects do not participate actively, that the information treated is of low sensitivity, and that the benefit clearly supersedes any harmful effects (Kalleberg, Balto et al. 2006: 13-14).

Committee clearance

In Norway, clinical research requires clearance from the Regional Committee for Medical and Health Research Ethics (REK), which requires a great deal of planning and hypothesizing beforehand. This is a challenge in anthropology as is difficult to state clear-cut goals and potential benefits when working within the logic according to which empirics come prior to theory, and the former informs the latter, rather than the other way around. That is not to say that the researcher undertakes her project with no preconceptions or no notion of what to observe and why—Gadamer illustrated the impossibility of such an attitude long ago (1989). Nevertheless, in contrast to certain other types of research—medical for instance—the ethnographer does not posit a clear hypothesis to either confirm or disprove in the field.

Drawing upon the principles of ethical clinical research as set out by Emanuel, Wendler, and Grady, as well as from the National Research Ethics Committees, I stipulated that while in the clinic, I was not to interact with the patients, either verbally or physically. Although certain aspects of nursing care, such as changing sheets, washing a body, cleaning instruments etcetera, would indeed have been within the realm of my abilities after instructions or aperiod of training, I abstained from all such activities. It would be impossible not to obtain sensitiveinformation about the patients whilst talking with staff or during rounds. Further, what exactly constitutes sensitive information could be a subject of discussion. Information that I judged to be so however, was easily excluded from the documented results. In general, singularizing or identifying personal information about any person encountered in the clinic was altered, and anonymized. It would then appear that no harm would come to the vulnerable population in question due to of my ethnographic research in the clinic. Furthermore, I did believe, and still do, that the study could prove useful in enhancing knowledge of the particular field. According to ethical committee standards therefore, I was well within my rights, and I was granted permission to conduct my study without modifications. Indeed, all the committee had to say, was that as long as I "just observe," the rest was up to me.

Problematizing institutionalized ethics

There are problematic elements with this type of approach to research ethics. The institutionalization of any field turns it into a matter of expertise and of compartmentalization. Institutionalization and category-making are ways of placing responsibility, as it *responsabilizes* some, while relieving others (Higgins 1999). If you have clearance from the committee, you are "free to go" and can feel good and justified about your practice. Is this enough? What is more, we saw that the National Ethics Committee defined research ethics as based on societal morals. This is problematic, both logically and empirically. By legitimating research practice from *actual* practiced societal ethics (which is in itself a somewhat dubious term), these guidelines make a jump from descriptive ethics to prescriptive ethics. This is bad logic: stating how things are and how they should be are not the same activity, and one does not follow from the other. If research ethics were based solely in societal morals, they would be entirely relative and cannot be judged to be good or bad, sufficient or insufficient in themselves, but simply so with regard to a specific societal context.

Ethical guidelines are indeed necessary for research involving humans, particularly vulnerable, ill or institutionalized individuals. In order to avoid researchers' ambitions or curiosities going "off track", limitations should be enforced. Nonetheless, there is much more to research ethics than what can be summarized in a guiding document. Research involving human beings carries much potential for exploitation. This calls for a certain *moral stance* on the part of the researcher. It is not simply about making sure that you stay within the ethical guidelines. Ethically conscious research on vulnerable populations requires, in my opinion, a continuous reflexivity. Continuously reevaluating the practice, and how we relate to the field, is a necessary exercise. Ethical committees work as "garde fous"—that is, institutions set up as fences against blatant abuse, but they are not, nor can they be, gatekeepers of morality. In a discipline such as anthropology, or when ethnographic research is undertaken in general, there is no way to plan for or foresee all eventualities of the field. Indeed, if there were, the endeavor would be pointless! To have the privilege of seeing is an exercise of power. The ethnographic field emerges and is co-created with the ethnographer. Thus, in line with the phenomenological insight that observation involves input and output, as well as Mol's perspective of multiple enacted realities (2002), we must admit that the researcher and her account necessarily enact the field in a particular way. Consequently, the ethnographer is at least in part accountable for it, and therefore cannot outsource ethics to a committee of any kind.

Thus far, I have looked at the ethics connected to the execution of the fieldwork. As the object of my study was "ethical and existential issues," and I now turn to the frameworks for interpreting the data and observations from the field.

Ethics of life and death

Bioethics and the four principle approach

"The Four Principles of Bioethics" were coined and detailed by Beauchamp and Childress in 1988, and have since become a classic upon which bioethicists as well as medical ethicists tend to base their discussions. The four principles of bioethics are beneficence (do good), non-maleficence (do no harm), respect for autonomy/self-determination, and justice. They are generally accepted in medical and clinical ethics today, albeit with certain differences in emphasis. For instance, in the Anglo-American context, autonomy tends to be held as "first among equals" (Gillon 2003), whereas in traditionally more paternalistic contexts, such as France and Spain, beneficence would oftentimes take precedence over autonomy. In my experience, these four principles color the way in which health care professionals think and phrase their decisions.

Primum non nocere—to do no harm—has been the core principle of the medical profession since Hippocrates, and I believe that the other three principles certainly make intuitive sense to the contemporary interlocutor as well. Few would be surprised to hear that doctors prefer to behave justly, or that nurses find treatments that may cause harm to be problematic. To be sure, these are not simply ethical principles of medical practice; they are embedded in common morality and secured in the law. Consequently, I envisioned analyzing the empirical material and the ethical concerns of the field through a lens of these principles. However, these principles were oftentimes ill-suited for understanding on-site processes. Not because they are false. When a physician says; "Let's see what is best to do here. We have to think about what is most just" or "We have to value the patient's autonomy," then this certainly reflects a set of values. Yet the level of abstraction involved is such that this could mean just about anything. It is for this reason that Komesaroff (2008) argues that despite theirwide audience, bioethics is limited. It simply does not accommodate the wider variety of ethical goals that medicine serves. In Komesaroff's view, the four principles also rely on theories that are questionable in themselves. Furthermore, and more importantly in the context of my project, bioethics has a tendency to frame questions in a vocabulary of "dilemmas." When it comes to real-life, small-scale decisions, actions and reactions, "dilemma" might not be the best concept. More often than not, I believe we do not perceive things as a dilemma until retrospectively. The four principles are unable to provide an adequate account of day-to-day decision making in medicine, Komesaroff argues, stating that medicine and conventional bioethics are further apart than ever (2008: 23-25).

Rather then, I found theories that more or less explicitly build on the ethics of the classical Greek philosopher, Aristotle to be of much use. In Aristotelian ethics, practical wisdom—*phronesis*—is emphasized as a key component of ethics, non-reliant upon metaphysics and reliant rather on a cultivation of virtues and understanding of concrete situations. Aristotelian ethics differ from both deontological or consequentialist approaches, and recognizes that not all behavior that has ethical content occurs in a theoretical discourse aimed at universal norms. I found that conducting sensuously engaged research in the clinic exposed instances of what we might call *microethics* (Guillemin and Gillon 2004, Komesaroff 2008) or *ordinary ethics* (Michael Lambek 2010). By this, I mean small-scale, real world ethical concerns, often not dealt with in the bioethical literature, either because their mundane character makes them seem uninteresting, or because they resist abstraction. Ethics in this perspective is an unavoidable part of the human condition, yet it is not necessarily spectacular or grand. Ordinary ethics takes place without calling much attention to itself, and is often grounded in practice rather than knowledge and belief (Lambek 2010: 1-2). This approach has colored all my work, and it comes across clearly in article 3, where I explicitly employ the perspective of microethics to analyze non-treatment decisions.

Microethics

Microethics starts from the premise that clinical practice consists of an accumulation of barely discernable ethical events, by which it seeks to reveal "the structure and the dynamics of the clinical interaction and in particular to explicate the actual processes involved in clinical decision making" (2008: 33). As such, it is the field of day-to-day communication and structured, complex interactions, subtle gestures, and finely nuanced language (2008: 29). Not all behavior that has ethical content occurs in a theoretical discourse aimed at universal norms. In particular, medicine must be understood as a complex set of value-laden practices embedded in the social and cultural structures of an ever-changing society (2008: 15). According to Komesaroff, both doctor and patient are engaged in an unbroken continuum of ethical decision-making in the course of the clinical interaction (2008: 27). This does not simply include words, but the manner of their delivery, the tone of the voice, facial expressions, as well as the degree of interest and compassion. The little things, such as the time taken, the communication of commitment and concern, or the sensitivity of the touch, are of ethical importance. In the words of Le Breton:

> Mimic, gestures, postures, the distance from another, the way of touching him or to avoid it whilst talking to him, looks, are all the matter of a language written in space and in time. (…) Even if speech is quiet, the movements of the face and of the body remain and testify to inherent meanings of the face to face or of the situation (Le Breton 2004: 47).

This however, calls for an embodied approach to ethical discernment. To this end, I wish to argue the utility of emotions and affective reactions.

Emotional reason

We exist in the world affectively, writes David le Breton (2004: 129). The concept of affect dates back to the philosophical works of Spinoza, and the academic literature on the topic is abundant and nuanced, where different authors of different disciplines have their own takes on the concept. Tying in clearly with the phenomenological tradition, Gregg and Seighworth provide this description:

> Affect arises in the midst of *in-between-ness*: in the capacities to act and be acted upon. Affect is an impingement or extrusion of a momentary or sometimes more sustained state of relation *as well as* the passage (and the duration of that passage) of forces or intensities. That is, affect is found in those intensities that pass body to body (…) *and* in the very passages or variations between these intensities and resonances themselves. (2010, 1)

Affects are forces present in all encounters. It is somatic, instant, and unreflective. Most authors therefore differentiate between affect, on the one hand, and emotions on the other. As Hemmings says: "affect broadly refers to states of being, rather than to their manifestation or interpretation as emotions" (2005: 551). In all interpretations affect positions us clearly in-this-world, in-the-flesh, in-the-mind, in the physical realities of our lives and our surroundings, and the experiences that we are subjected to both as actors and as acted upon. Emotions on the other hand, are thought to be reflexive and self-conscious. I nevertheless believe that for practical purposes, the lines between the two are oftentimes blurry indeed.

What then, is the value or utility of emotions and affect? In the introduction to her extensive philosophy of emotions "*Upheaval of thoughts,*" Nussbaum makes a strong case for the value of emotions in human intelligence, arguing that they may be viewed as intelligent responses to perceptions of value. I believe the following argument deserves to be quoted at length:

> If emotions are suffused with intelligence and discernment, and if they contain in themselves an awareness of value or importance, they cannot (…) easily be sidelined in accounts of ethical judgment, as so often they have been in the history of philosophy. Instead of viewing morality as a system of principles to be grasped by the detached intellect, and emotions as motivations that either support of subvert our choice to act according to principle, we will have to consider emotions as part and parcel of the system of ethical reasoning. We cannot plausibly omit them, once we acknowledge that emotions include in their content judgments that can be true or false, and good or bad guides to ethical choice. (2001: 1)

This, Nussbaum says, forces us to deal with some messy material. If many have disregarded emotions or affect, she argues, it may be because to acknowledge them challenges our image of self as an independent and self-sufficient actor. Experiencing emotions or strong affects, does make it painfully clear how dependent and needy we may indeed be. To be affected by something or by someone, is to experience that these things or these persons make a difference (good or bad) in our existence: That things that may be out of our control, has an effect upon our well-being and our capacities both physical and mental—often a difficult realization indeed.

This is not to say that affect and emotions should be trusted uncritically. Nevertheless, they are an integral part of our intelligence. This is illustrated by the fact that persons who lack certain emotional registers, such as empathy, reason in a significantly different way than the majority of people (Howe 2013). Emotions can be seen as "evaluative reactions" and "to endorse an evaluation is to endorse some emotion as appropriate" (Baier 1990: 18). As such, affect and emotions are a source not only of knowledge, but perhaps *particularly* of ethical discernment.

Affective and emotional responses may also be a source of trouble, as Rushton et al. elaborate in their article on moral distress among palliative care clinicians (2013). The authors argue the importance of moral sensitivity, defined as the ability to recognize the presence of moral issues in real-world situations, to discern the morally salient dimensions of a situation and to perceive and interpret the perspectives, feelings, and responses of others all the while discerning how one's actions may affect others and one self. Arousal involving ethical quandaries, they write, can occur due to value conflicts (e.g. when the requests of a patient or a patient’s next of kin go against what a physician considers to be consciable or the most beneficent option), confusion about the proper course of action or uncertainty about which course of action to pursue, as well as a real or perceived inability to “do the right thing” (2013: 3). In such cases, a lack of moral sensitivity, Rusthon et al. write, may lead to a failure to recognize occasions for moral action and “Overlooking the negative impact of certain behaviours on patients, families, and others, may lead to inappropriate acts that undermine integrity” (2013: 2-3).

Part 3. Three hospitals

> It is still dark outside when I leave the house. The traffic is subdued, flowing. A boat drifts quietly down the river. The air is crisp and chilly. I get on one bus, and then another. By the time I arrive at Central hospital, it is starting to be light out. There are approximately three passengers on each bus, which allows me to eat my banana in peace, whereas during rush hour, I would have to be standing. Central hospital reveals its impressive size in the morning when the streets are empty. It is like a small city, and I get off at the second to last stop. Bathed in the cold light of the sky right before the sun rises, I take a few breaths of fresh air before entering the halls, knowing that the rest of the day will be spent in the hot, enclosed, purell-smelling halls of the adult intensive care unit. It is still quiet in the entry hall, and I enjoy the sweet smell of freshly made pastries that fills the air from the kiosk. I traverse the hall and turn down several corridors. I change into my inside sneakers and white scrubs, and go to ICU. I type the code, and the heavy doors open. Already in the entrance, I can hear laughter coming from the break room. On the inside of the big double doors, the world never sleeps.

In this section, I shall describe briefly each field site. Thereafter, I will pay more detailed attention to what I call “the room of the patient.” There were differences between the rooms in each clinic, of course. Yet important similarities remained. It is important in order to understand the dynamics of a place such as the ICU, to have an impression of what a patient’s space might look, smell, and sound like. As some might remark, there is very little mention of the people working in the different units. I go in to this only briefly. Naturally, each person who works there; physician, nurse, and auxiliary aide, does play a role as an individual. Their mood, interactions with patients, next of kin, as well as with their colleagues, all differs. As do their break patterns, preferred lunch partners, and so on. Nevertheless, in the complex network that is the intensive care unit, each person is to a high degree interchangeable. The ICU is a place in itself and onto itself. The people come and go, when one nurse’s shift is finished, another one comes to take his place, and this continues day after day, night after night, without any noticeable difference to the ICU itself, or to the dilemmas and dramas that take place concerning its patients. In my opinion, this supports the fact that *this particular thesis,* is about a form of medicine, a practice, a space—to borrow the words of Zussman (1992)—and not about the individuals therein.

Hospital North

Hospital North is a large university teaching hospital in Norway, and is the primary hospital of its district. The buildings are relatively new, following a grand renewal and remodeling of the entire hospital complex only some years ago. It makes up almost a small neighborhood with streets in the middle, cafés and kiosks on every corner. Hospital North houses a total of three intensive care units; one neonatal, one pediatric, and finally one adult *main intensive care unit*. My fieldwork was limited to the main adult ICU. This unit accepts all categories of adult intensive care patients, both medical and surgical. Most resident patients during my stay were aged between 50-60. The unit has a total capacity of 12 patients, which includes utilizing some extra rooms, which are considered sub-optimal and are normally used for storage.

In this hospital, no patients administratively belong to the ICU. They are all formally admitted to other units, such as gastric surgery ward, neurology, cardiology etcetera. This also means that the ICU is never the first stop on a patient's hospital journey: they all come in, either through a medical unit, through elective surgery or the emergency room and subsequent surgery or admission.

The ICU is a closed unit that may only be accessed with an electronic key card. The day in Hospital North starts at 7.30 with two separate morning meetings; one for the doctors and one for the nurses. Each professional group is briefed on the agenda of the day, and of the different patients in the unit and what they will be working with that day. Doctors make their rounds about 9 o'clock, and move around depending on patient needs. There is at all times one nurse assigned to each room—two in special cases where the patient is considered especially demanding (especially if their state is highly unstable, if the next of kin is very demanding). A few nurses per shift move around and have the denomination “loose.” They do equipment maintenance, fill out logs, count medication, and help the other nurses assigned to rooms.

Central Hospital

Central hospital is a very large hospital complex, constructed it appears, piece by piece and developed over time. Situated on the outskirts of town, it is one of the largest teaching hospitals of the region. One bus line even runs through the property, as many of the buildings are not in walking distance for persons with reduced mobility, and many are constructed on a slant hill. Parking lots and small grass lawns surround the complex where patients are often times transferred by ambulance between one building and another.

Central hospital houses several intensive care units. Apart from the pediatric and neonatal units, there were two adult ICUs: one surgical and the other medical. My original agreement was to conduct ethnographic research in the surgical unit. I was quickly notified however, that within a few months, the two units located across the hall from each other would be merged into one unit. This was a subject of much contention for many, particularly the nursing staff. One day when I popped my head into the doctors’ office, one of their colleagues from the other ICU was there, and when he heard what I was doing he jokingly reproached me for not taking an interest in *his* unit. Careful what you wish for, I told him. I just might take you up on your request! The doctor retorted that yes, I was welcome at any time.

My fieldwork in France had been structured to two periods, each of two weeks. When I returned for my second period, I realized that while the break had been fruitful in terms of processing of data and impressions on my own part, it had the unfortunate side effect of somewhat removing me from the inner circle. The staff had all gotten more or less used to my presence, and I felt like I was “on a roll,” yet returning, this feeling of momentum had lessened. I decided therefore to pay the adjoining ICU a visit, and got one of the senior doctors from the surgical unit to accompany me and make the proper introductions. A decision was quickly made to spend the rest of my stay on the medical side. As the two units were in the process of merging, this made even more sense. I have decided to name these two ICUs “ICU left”—the surgical one, and “ICU right”—the medical; referring to their location in the halls of the hospital.

ICU Left is a surgical ICU with 15 beds, of which maximum four may be utilized for *sipo* patients; patients in recovery from heavy surgery. These patients are not really intensive care patients, and usually leave the unit after a day or two, having received extra attention during this time.

ICU Right is a medical ICU where in general, patients had not undergone any extensive surgery. The unit contains 15 beds all located in individual rooms. As the name suggest, it is located on the right hand side of the corridor leading to both ICUs.

On average, the patients in Central Hospital during my stay weree middle aged and up—only a few “young” (below 50) patients entered the unit in the time that I was there. The level of severity of the patients varied widely. Here too, the ICUs are closed behind heavy electronic doors that may be opened by typing a code. In practice, however, the doors are often jammed open.

Nurses work 12 hour shifts, lasting from 7:00 to 19:00, and 19:00 to 7:00. The work schedule of the physicians was less clear, it appeared they would arrive around 8:00 in the morning and stay until the work was done. Many, especially young interns stayed past 19:00 in the evening.

Hospital South

Located on top of a slant hill, overlooking on the one hand, the countryside surrounding the city, mountains looming in the far distance, and on the other hand, a small park giving way to an arid, industrial outskirts area, Hospital South is the smallest of the three hospitals. Yet it holds the largest intensive care unit. Hospital South is a university teaching hospital located in a medium sized city in the Spanish province of Cataluña. The structure is composed of two main buildings, connected by a third building giving the entire complex the shape of two connected, toppled over, bold case Ts, one being turned upside down. Built with dark red bricks, the buildings take on an impressive, thoroughly institutional air. Parts of the hospital have been remodeled in recent years; others are somewhat in need of a touch up. The halls of Southern hospital are always buzzing with people coming and going, and waiting. There are two adult intensive care units, both located on the sixth floor of the oldest building. Above the thick walls, the sign "Unidad de Cuidados Intensivos"—Intensive Care Unit—is clearly marked, and access beyond this point is restricted to personnel or next of kin accompanied by doctors. As I later realize, the doors are not, in fact locked as the electronic locks are broken, and in reality, anyone could come and go as they please. They do not, however, as Hospital South's ICU has a very restrictive policy on next of kin, allowing them only three slots per day, of 15, 30 and 60 minutes, in which they can visit, entering no more than two persons at a time.

One ICU is especially reserved for cardiac patients, and the second is larger and is a combined surgical and medical ICU with a total capacity of 26 beds divided into three smaller sub-units with very different lay-outs. The patients in Hospital South were on average much younger than in the two other hospitals, many of them being below the age of 30.

The day starts at 8:00. The early shift for nurses is from 8:00 to 15:00, the afternoon shift from 15:00 to 22:00 and then the night shift runs from 22:00 to 8:00 the next morning. The doctors start at eight as well, and at 8.30 receive information from the doctor who was on call the previous night. They then do rounds to check on their patients, do whatever has to be done, and at 12:00, there is a second staff meeting where all patients are discussed.

Who works in Intensive care?

The professional groups that populate the intensive care unit vary somewhat between the three countries. This is also a question of hospital organization. Although I chatted with the different categories of staff; physical therapists, cleaners, porters, students… My focus was on physicians, nurses, and to a lesser degree, nurse's aides.

In Norway, intensive care physicians are usually doctors specialized in anesthesiology who have thereafter taken a supplementary education specifically in intensive care, which lasts two years. Thus in the unit, one could find both intensivist specialists—these were always the ones in charge and anesthesiologists who typically also worked in surgical wards. Nurses all have a three year degree, recognized as a Bachelor's degree. Working in an ICU, however, requires two years of experience after graduation. Many nurses in Hospital North also had a supplementary degree in "intensive care nursing," a one and a half year specialization.

In France, physicians working in the ICU were specialized in what is called "anesthésie-réanimation", that is anesthesia and intensive care, a combined specialty. Some split their time between surgical blocs and the ICU. Others were employed only in the ICU. Nursing in France is a three-year education; however, it does not have the status of a Bachelor's degree. There is no supplementary specialization in intensive care, and nurses may start working in the ICU right after graduation.

In Spain, physicians in the ICU had a specialization in intensive care medicine. Some of the intern physicians came from other programs, such as gastric surgery, anesthesiology, which required them to have experience from intensive care. Nursing is a four-year "grado", undergraduate program. Nurses may enter work in the ICU after obtaining their nursing diploma. In fact, many of the nurses with whom I spoke in both hospitals Central and South were fresh out of nursing school, and many of them had not requested (nor, in some cases desired) to work in intensive care. Depending on the place, they would receive between one week and one month of on-site training as ICU nurses upon employment. Not surprisingly then, perhaps, most nurses in Hospital North expressed working in the ICU as being an active choice and a decision made based on their interests for working with critically ill patients and in a high technological setting, whereas in Hospitals Central and South this was the case with a few of my informants only. Most had simply been placed there. Given a very difficult work situation, particularly in Spain, where unemployment among the young between 16 and 25 years of age is around 45%, one does not turn down an offer of employment lightly. In Central Hospital, it was generally the working conditions more than the work itself that had attracted nurses to the ICU. Contrary to most units, the ICU worked in shifts of 12 hours, which meant more days off to compensate for the long hours.

The nursing education and the high formal demands for someone to become an intensive care nurse in Norway as opposed to both France and Spain, might explain, in part, why it was considered most natural in Hospital North that I should spend my time with the nurses, whereas this was not the case in Hospitals Central and South.

The room of the ICU patient

> The room of a patient creates a cotton ball, encapsulating feeling. It is as if nothing else exists outside of that particular space, the silence of which drowns out any outside noise. The room is its own technical organism, breathing to the rhythm of the ventilator sounding like a heavily sleeping old man. The occasional alarm chimes, liquid squeezing through the tubes. Haaaa-pfffff, haaaaaa-pffffff. This is the pulse, not only of the patient, but also the observer, who breathes in sync.

I believe that what most people first notice when they enter the room or the assigned space of an intensive care patient is the bed and the extensive machinery surrounding it. Indeed, the bed is an impressive contraption in itself. In Hospitals North and Central, the beds were highly technical, and had a panel of buttons on the end, serving to weigh the patient lying down, as well as lift up and down and tilt to the sides. The beds are somewhat smaller in Hospital South, where equipment looked smaller and less "impressive."

On both sides of the bed, next to the patient's head, are stands with equipment. Once, in Norway, a nurse referred to the right hand side as the "*wet section*", and the left hand side as the "*dry section.*" The system was similar in all three places. Fluids dominated the right hand side, the wet section. All medication, fluids and nutrition in case of liquid nutrition are administered from this side. In Hospitals Central and North, this was also consistently the side on which the syringes were located. Hospital North had an elaborate apparatus for this, that I have labeled the "syringe apparatus." It is a tall block-ish thing, where containers of medicine and drugs are inserted into the side, timers are set with corresponding buttons, and the end of the container is connected to a tube inserted in the patient. The nurse then sets the machine, deciding the dosage and time slot, and the machine pumps in the medication. In Central Hospital and Hospital South such equipment was used less frequently, and more often, I would see nursing staff preparing syringes of medication by themselves, either to be administered mechanically, but also manually.

The "*dry*" left hand side of the bed held the most important monitors. I found that a typical patient would have two monitor screens, each with different graph options. The monitors show heart rate, breathing, blood pressure and have the possibility of showing a whole lot more such as pressure in the brain etc., depending on patient situation. It is generally connected to the ventilator. These screens are for the most part under the doctors' control. Nurses may push certain buttons, but the "dry side" belongs mainly to the doctors who determine the settings. The typical patient is connected to as many as 20 tubes and catheters. Depending upon their injuries and their illness, they may also have supplementary equipment such as a dialysis machine, always located on their left hand side.

In Hospital North, all patients had individual rooms, and these were large and spacious, all facing a river. The windows covered most of the wall towards the outside, and under them was a workbench with drawers for equipment and a small radio. In the corner toward the hall is the nurse's desk containing a computer, a list of medications and relevant files and an anti-bacterial liquid dispenser. Each room holds three extra chairs, two rather straight ones, and one more comfortable, resembling a stripped down version of a living room recliner. The upholstery is a light beige leather-like material. In France, rooms were somewhat smaller, but all patients were placed in individual rooms. Most of the rooms had windows facing outside, with the exception of four of the rooms in ICU Left, as these rooms faced the inside of the ICU. On the far side of the rooms, like in Norway, is a long bench, divided in two. One half was supposed to be used by the nursing staff, the other one by nurse's aides. In practice however, this was not upheld. In Hospital South, the three sub-divisions of the unit appeared to reflect three stages in the development or build of the ICU. Consequently, one had no individual rooms but the other two did, the most recent of which had large, spacious rooms painted in a light color overlooking the hills in the distance. In the sub-unit without single rooms, patient "boxes" were located along each side of the room. The nurses station was situated by the entrance of the room, facing the far off windows on the opposite wall.. Patient spaces were divided by half-walls, but all beds faced inwards towards the middle of the room. A line was drawn on the floor in front of each bed in order to demarcate where the patient's space began and the general space of the sub-division ended. None of the rooms in Hospital South, including the most recent, had workbenches or sinks inside. All preparation of medication therefore, was done on the outside of the room, on trolleys, alternatively on trollies brought into the box.

On the inside of every patient room, in all three hospitals, there was an antiseptic container hanging on the wall, and visitors as well as personnel are expected to clean their hands both when entering and exiting the rooms. In general, next to all nurses' stations and equipment storage, trollies and sinks, there are such containers. The rooms in Norway had containers on the inside holding dispensable aprons and gloves, which are routinely used before handling any patient. In Central Hospital, such dispensers are wheeled around on trollies, moving between rooms. In Hospital South, these were sparsely used. Oftentimes an apron hung upon a hook inside the room, and staff alternated putting them on to examine the patients. Next of kin had assigned aprons, which were not thrown away after each visit, but hung in the hallway for multiple usages.

One reason for the large rooms in Hospital North, is that there is one nurse assigned to each patient at all times. The nurse had her or his own desk and chair in a corner towards the hallway, containing a computer and all information about the patient. In both other hospitals, nurses had more than one patient at the time, and do not spend more time inside a patient's room than what is deemed medically necessary. In Central Hospital, not staying inside the patient's room was seen as *ideal*, as in favor of the patient's peace and privacy. Furthermore, there were no chairs inside the rooms. In Central Hospital however, most rooms were equipped with flat screen TVs. In Hospital North, one room had a television, but there were radios in each room.

In the midst of everything, the patients themselves are oftentimes hard to notice. The visual impressions are overwhelming. Nurses and physicians may sometimes have to remind themselves of the patient's presence when faced with making decisions and evaluating information that is largely technical in nature. Indeed, sometimes the patient will appear small and bird-like in the enormous bed, especially in situations where the patient is heavily sedated or asleep, when their limpness and expressionless faces and bodies make them easy to overlook. In many cases, sedation and superfluous liquid erase their individual features, and the steady flow of liquids causes the body and face to swell. Patients are weighed every day, and some may weigh around 20 kilograms more than what they did upon arrival due to excess fluid. In fact, I have occasionally made mistaken assumptions about a patient's age and even about their patient's gender. Some will look much younger due to the swelling in the face. Others seem to gain decades. The sheer lifelessness of the heavily sedated, long-term ill may cause them to take on a particularly blood drenched, greyish complexion and they appear irremediably frail and old in the large bed. Long term patients lose muscle, and may look quite thin and ungroomed. That said, the personnel do groom the patients. When it is possible, they wash their hair, and they comb it regularly. However, legs are unshaved, toenails often remain unclipped and after around one week of hospitalization, the physical appearance of a person may be quite altered. As a nurse said jokingly, "You sure don't get more beautiful by being here! You may lose a bit of weight due to muscle loss though." Some patients in intensive care can ingest food. Most receive nutrition intravenously or directly into their stomachs, as they receive mechanical breathing aid through intubation or mask. Feces and urine are closely monitored, and in many patients, these leave the body via tubes into bags hanging from the sides of the bed. In Central Hospital, most patients, with the exception of those who are fully unconscious or fully awake, were tied to their beds. This was for their own protection, so they did not accidentally rip out any of the equipment or tubes. It does nevertheless make for an uncomfortable sight, and some patients have a hard time with it. This is not done in Hospital North, where nurses are always present. In Hospital South, despite nurses rarely spending "unnecessary" time in the patients' rooms, restraints were not used and the staff was quite negative toward such a practice.

Clinical-ethical and existential issues revisited

In this last section of the synthesis, I expand on the ethnographic discoveries. In doing so, I revisit some of the questions raised earlier in the theoretical section, now in light of empirical observations. Some parts deal rather explicitly with topics that are detailed and elaborated in one or more of the articles, such as conditions of personhood, dignity, and dying. Other observations pertain to other aspects of ICU work, for instance considering the potential taint associated with working in the intensive care, and attitudes toward “difficult” patients.

The condition of patienthood

> We enter the room, which is shared by two patients, their respective spaces being separated by a curtain. On the wall, facing both beds hangs an old television set. The patient closest to the window, an elderly woman accompanied by her husband is watching a daytime show. The doctor approaches them and asks the husband to leave, so that we might conduct the confidential conversation with the patient closest to the door. The man leaves the room, and the lady is clearly unhappy with the situation, more specifically with having to turn off the TV that she has paid money to watch.
>
> The doctor turns to the patient, who is very ill. She is complaining of severe abdominal pains, of which the origin is unclear. The patient is only a few years older than I am. She has been informed that she is HIV positive, but the medical team is not confident that she has understood the information. She is an immigrant, probably illegal with no family in this country and apparently no friends—or rather, none who will come forward. The doctor talks in a friendly tone, choosing her words carefully to avoid difficult terminology when asking about her symptoms. This includes trying to get a detailed account of the nature, frequency, and texture of her recent bowel movements. The patient occasionally looks over at the medical students and I. The pain is visible on her face at all times, but her explanations are limited by her poor command of the language. She makes sporadic outbursts saying “Pain!” “Pain!” The doctor then moves on to do a physical exam, as the two medical students watch on. The elderly woman on the other side of the curtain remains in her chair, clearly within earshot. While examining the body, the doctor turns to

> the students and starts using medical terminology to describe various symptoms, manipulating her limbs, palpating the skin and abdomen. I stand in the corner of the room, with my back against the wall—a tip for dealing with malaise that I picked up in a previous conversation with another medical student.
>
> The patient's eyes flicker. It seems she does not understand what is being said about her. "What", she tries, "are my eyes yellow?" "Is that bad? "Pain. Pain". Her fear becomes almost a palpable quality. Suddenly, I am afraid I might pass out. Clutching the wall is no longer enough, and I look away, stare out the window. Think about something else. Anything else. Finally, I pretend to receive a text message, and slip through the door as discretely as I am able to. I walk past corridors of people, my vision hazy, until I find a set of stairs where I sit down and look onto the floor, trying to settle my stomach, wiping cold sweat from my forehead.

Medical conversations involve two sets of voices: the voice of medicine and the voice of the lifeworld; two voices that oftentimes collide (Charon 2011). This ethnographic note reflects the existential harshness of the 'business' of intensive care. Ironically, to be sure, as this situation took place *prior* to admitting the patient to the ICU. For the most part, Charon argues, doctors are ill-equipped to deal with many of the "human" or existential aspects of their job. Instead, opportunities for real contact are squandered out of fear and ignorance, the sick person being left "having had withheld *exactly* what is needed at the time of acute serious illness—the assurance that one is recognized" (2011: 35-37, emphasis in original). "Why am I not being treated like a person", de Zulueta writes, is a near universal lament in healthcare (2014: 90).

As I believe we see in the situation above, however, such suboptimal interaction is not always due to a lack of skill on the physician's behalf. Indeed, I knew this physician to be a highly sympathetic and pleasant young woman, who seemed to genuinely care about her patients. In fact, there is an inherent quality to patienthood, and of benefiting from care, that elicits suffering. As Frank (2001) notes, suffering in illness is exacerbated by having to submit said suffering to medical *workers* for whom the patient is just another task (2001: 361). Moreover, once the body *belongs* to the hospital, it becomes a teaching tool. In the situation above, this was further exacerbated by the language barrier. The fear, physical pain, and visible alienation displayed by the patient when the doctor turns to what is indeed the second part of her job; to educate students, was painful to watch. Here, she is no longer even attempting to interact with the patient, but talks about her, over her, and using Latin terminology no less.

This was a recurring feature in the three ICUs, as they are all dedicated to medical and nursing education. The patient's body belongs to the hospital, to the unit, which, closed, as it may be to the outside, is entirely open to insiders. Several times, especially nurses would complain to me about surgeons and their brash, single-organ-focus, and disrespectful behavior, or of medical students who entered the unit touching and seeing everything. "Do the students need to see the patient's naked body when they come in here to learn about the machines?" An experienced nurse once asked rhetorically. Moreover, in one of the interviews, a doctor told me how oftentimes the first thing a wake patient would ask for would be clothes of some kind. "But we don't do that here", she retorted. "It's not possible."

It is tempting to conclude that there is no room for modesty in intensive care. My experience however, is that there is an extended form of modesty, where the caretakers become included into a patient's intimacy. As a nurse's aide in Central Hospital revealed in our interview:

> "Cleaning someone who has just soiled themselves… It is something quite intimate. But if you only knew how relieved and grateful they feel. And for you to be cleaning it up, it is degrading when you see it from the outside, sure. But in fact, it is an amazing act to be doing" (French nurse's aide).

Alternatively, the great care that I witnessed in Hospital North where a nurse vetted her thoughts with me on whether she should put a headscarf on her patient who was bold from chemotherapy, yet who was fully unconscious, condition deteriorating, and incapable of providing any input. Concerns with bodily integrity, and matters that could sometimes be perceived as purely aesthetic prove important to the understanding and promotion of patient dignity in the ICU. It is also connected with the enactment of personhood, alternatively with its suppression. I deal with these issues in greater detail in Articles 1 and 2.

The experience of suffering

I sit down next to the young nurse at her station. We chat a bit about her pending transfer to another unit, about shift work, and about nothing in particular. The patient she is tending to is elderly. It is hard to tell just how old; he could be 70, he could be 90.. This particular patient is quite ill indeed. They've recently done an MRI because there was a suspicion of a brain hemorrhage. Together with another nurse who has entered the room, they read the MRI transcript. Although they admit that they do not understand all of it due to the technical medicinal language, the nurse explains that the results do not show any hemorrhaging—yet the situation is dire. His overall state, she tells me, is so bad that things just shut down. Moreover, such systematic shutdown causes muscle atrophy. I must be visibly horrified at the prospect of this, because the nurse reassures me that the condition is reversible with physiotherapy. Yet some patients spend six months to a year to recover to their "old selves." She approaches the patient and looks at some graphs, then returns to her post by my side, walking heavily. "We could all get this sick, eh," she comments with a slight sigh.

The patient is somewhat awake now. Has been given medication to sedate him, but they have yet to take effect. In the meantime, he struggles to breathe due to slime in the lungs and throat. He also appears to be in pain because there are slight movements in his legs that protrude from the white sheet covering the rest of his body. He groans. The noises cannot be understood as words, but it is clear that he is trying to communicate, because the intonation is discernable. He tiredly lifts his arms to try and remove or adjust the mask covering his face. The noises grow louder, and the nurse gets up and stands by the patient's head, lowers his hand and asks him rhetorically if he is finding it hard to breathe. "Move your head to the side; you'll see it's easier to breathe." "Is breathing hard?" "Hey Lars, you have a mask helping you to breathe, okay?" She returns to the post. It happens again. He groans, lifts his hands and tries to remove the mask. She walks back to him. "Is it hard to breathe?" "Hey, Lars, the mask is there to help you to breathe, okay?" No later than the nurse having sat down, he groans again, moves in the bed, tries to remove the mask. Once again, the nurse gets up slowly walking calmly over to his side, and says "Lars, hey Lars, is it difficult to breathe?" "The mask is helping you, okay?" She does not

> change her tone, she does not let up. There is nothing to do but wait for the medication to take effect. I am equally impressed by her endurance and low key empathic behavior, as I am frustrated with my own impotence in the situation. The end of my fieldnote reads; *Hard to see this person suffer*.

The elimination or management of pain is a chief concern in any type of modern medicine. Twice did I experience patients moaning with pain. Overwhelmingly, patients remained thoroughly inexpressive in any conventional sense of the word. Yet, pain and suffering, as Ricœur reminds us (2013), are not the same thing. And silent as it may be, the ICU is a space replete with suffering.

Suffering, according to Frank (2001), involves experiencing one's self on the other side of life as it should be, and that no material resource can bridge that separation. In the words of Paul Ricœur, what is at stake in suffering, phenomenologically speaking is one's intentionality; the capacity to direct one's self toward something other than oneself. Suffering erases the world as a horizon of representation, leaving it to appear uninhabited. In Ricœur's analysis, suffering collapses both time and the self, and makes the *now* to appear without remedy, without room for reflection, or aim. "Reduced to the suffering self," Ricœur writes, "I am a live wound" (2013: 17 my translation[7]). Suffering resists definition. The medical model, potent as it may be against that which can be located, identified and thus manipulated, is ultimately powerless when faced with the undefinable (Frank 2001: 355).

It is not only the patients, however, who experience suffering. Attempting to understand my own strong, somatic reaction to the situation explained at the start of this section, led me to ask: Why was it that only a few days later, in the ICU, I was able to observe, with no problems whatsoever, as a nurse cleaned the black, coagulated, crusty blood from a recent surgical wound in the woman's abdomen, whereas I was about to faint at the sight of the patient, corporally intact, in a low-tech unit?

Suffering manifests through the face, Marin writes (2013: 47), and we are reminded of Levinas' theory of the encounter between faces. According to Levinas, seeing the face of the

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[7] Réduit au soi souffrant, je suis plaie vive.

other is an ethical calling to responsibility. Indeed, in the philosophy of Levinas, ethics is prior to ontology, and it is only in the encounter with the other that I may in fact also assert myself as a subject. Conducting observation of persons is a form of being-with. Even when they are unaware of one's presence—as is often the case in the ICU. The patient in the vignette at the beginning of this section was a woman, close in age to my own. She verbalized parts of her terror, and in a crucial moment, her gaze met mine. *I saw her and she saw me*. The calling was complete. A calling that, nonetheless, I did not answer.

Caretakers also suffer in their encounters. It may be written on their faces, like the young intern physician, who, during the afternoon staff meeting, keeps removing his glasses and rubbing his eyes, repeating how "there is something with patient X that evades us. Something escapes our grasp" (*il y a quelque chose qui nous échappe*). Or the nurse who sighs profoundly when asked which patients she's responsible for that day, saying simply, that "He's gonna die. He's gonna die like all our patients." The young woman from the earlier vignette was admitted to the ICU the same day, and remained a patient throughout the rest of my stay. Repeatedly during rounds, the physicians expressed concern not only for her prospects, which were bad, but also for the fact that they were unable to locate any family members, that they were unable to improve her condition, and that she might end up in an unmarked grave.

Paying attention to the suffering of caretakers is not without importance. As Rushton et al. write: "when arousal in response to another's suffering is not regulated, it can give rise to personal distress, thereby undermining the possibility for expressing compassion, leading to either avoidance or self-focused behaviors" (2013: 2). This insight might be helpful in attempting to understand some of the rather harsh reactions that I at times noticed among certain members of staff, particularly in Central Hospital. According to a Levinasian interpretation of the interpellant nature of the human encounter, this calls us to act and react. Failing to do so—for whatever reason, is therefore not simply experienced as difficult, but if experienced continuously it may pose a threat to the very subjectivity of the observer, who is inhibited from answering the ethical calling. When one becomes habituated to observing suffering yet insufficient means are provided, either materially or emotionally, in order to attempt to alleviate this suffering, the sense of powerlessness in the face of affective responses may, as Rushton et al. (2013) argue, lead to apathy, evasion, or even inconsiderate (unethical) behavior.

Intensive care as dirty work

> We are in the patient's room, and I observe as a young physician teaches a newly arrived medical student. They walk around the patient's bed, looking at the different pieces of equipment and tubes, the physician explaining what each element is for. "This patient is *curarized"*[8], the intern explains. "But he has no beep."[9] The intern lifts her head and all of a sudden looks straight at me—'it's inhumane.' "Me, my conviction is that it's inhumane to keep a patient curarized without putting them in an artificial state of sleep. In fact, there's no way of knowing whether or not they're awake. So maybe they're hearing everything, noticing everything that's going on. But they can't move at all" She locks eyes with me once more; "it's as if you were a prisoner in your own body." "I'm not very happy about it" she continues, as she moves around the bed. "I am *not* happy."

According to Hughes' influential definition, dirty work is labor that is "physically, socially or morally tainted" (1958: 122). Medical personnel, physicians in particular, have highly esteemed and socially valued jobs. Nevertheless, medical professionals and nursing staff perhaps much more so are routinely engaged in dirty labor. Mills and Schejbal (2007) write that nursing is a "genre of feminized work that qualifies as physically, socially, and (just a tinge) morally tainted" (2007: 113). Nursing is physically tainted due to the contact with bodily fluids and functions, possible bodily harm, as well as its proximity to death. Socially, nursing carries taint by virtue of the servile nature of the work (2007: 113). Technologies in healthcare have lightened nurses' workload. At the same time, however, this form of bureaucratization of the healthcare system has created new frames within which tasks have to be carried out. This has contributed to the dirty character of nursing by creating necessary but unvalued, banal, and time-consuming tasks. This corresponds well with Sotirin's (2007) analysis of secretarial work as dirty work. Sotirin's argument is that when important aspects of someone's work are dismissed as trivial and

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[8] Has been administered muscle-relaxing medication that paralyzes all the muscles in the body.

[9] A brain monitor indicating wakefulness or sleep

mundane, the status of those carrying it out may correspondingly be reduced to that of a servant. As Sotirin points out, the duties of a secretary can be both humiliating and onerous (2007: 95-97).

Nurses and auxiliaries carry out much of the routinized work of cleaning, and they sort out and move around equipment. In all the clinics, they are in charge of the personal hygiene of the patients. This, of course, includes intimate and private cleaning. Most patients are unable to urinate or defecate by themselves, let alone go to the toilet on their own. Consequently, bags of urine and feces, alternatively pots of their waste have to be emptied at regular intervals. In addition, the nurses regularly carry out the task of aspirating intubated patients. This is a procedure where slime and mucus is aspirated from a patient's trachea using a small plastic hose, which creates distinctive and unpleasant sucking and gurgling sounds as the slime is extracted. These procedures are vital to a patient's chances of recovery, as they combat bedsores, infections, and pneumonia. In many cases, however, it is a rather thankless job.

In Central Hospital, ICU Left had separated their patient population into groups of *sale* (dirty) and *propre* (clean). This was in relation not to their hygiene, but to the nature of their disease. Dirty patients meant more work, as they were typically underlain isolation either because they suffered from a type of infectious disease and were potentially contagious (e.g. swine flu), or due to severely compromised immune systems. Consequently, the hygienic and preventive measures to be undergone by staff both when entering the rooms, when engaging with the patient and upon exiting, were all the more strict.

In line with Frank's notion of "embodied paranoia", according to which the machinery of biomedicine is, despite its best intentions, also an actor of harm, I will argue that there is also a certain moral taint associated to work in critical care. On many occasions, I received clear indications from members of staff, regardless of their profession, that they had moral qualms or experienced unease about their practice. A physician told me he regarded the treatment of a few of the patients currently in the unit as "animal experimentation," by which he meant that their treatment had gone too far, that it was undignified and that it should have been withdrawn. Others simply seemed exacerbated by a perceived futility of their work;

> Treatment, treatment, treatment. Why do we do it? For the sake of the next of kin? So that their loved ones may be returned to them? For the sake of prestige and to show medical prowess? Out of a genuine concern for the patient? (ICU nurse)

Moreover, general unease about the number of elderly patients arriving in the ICU, many of them ending their days there, seemed to be pervasive. An experienced nurse's aide relayed the following story that occurred years earlier when she was new to the unit:

> We were working night. And we're told that an 80-something year old patient is arriving with the ambulance service. So, we're sitting down eating...we eh… we decided to start eating while we waited for her to arrive. And then we get the message that the patient (...) we're told not to wait anymore. She had died during transportation. We raised our glasses and toasted. Me, I was... I wasn't… I had just arrived at the unit. But I got it, eh. I understood. (…) They toasted; peace upon her soul. It was better for her. Everybody knew that it was better for her. She was 80 years old and she'd go to intensive care. When we learnt that she would no longer be coming in and that she had departed before… Well, hallelujah. She got away. She got a way. She escaped a violent death. Because it is a violent death: tied down, sedated, intubated... all that it's brutal. It's all *too* brutal.

A physician once said, in the space outside of a patient's room: "There may not be a heaven and there may not be a hell. But there is a purgatory and this is it."

These observations resonate with Zussman's analysis of two North American ICUs in the late 1980s (1992). In one of the clinics researched, the expression "cheechee" circulated. The origin of the expression is a joke about two missionaries who arrive in a tribal land where they are captured and given the choice between death and cheechee. The first missionary chooses cheechee and is subsequently tortured by the locals and then killed. Faced with the same options, missionary number two reluctantly chooses death. "Yes", the chieftain then says. "But first, a little cheechee." The point being, death is certain, yet death does not come easily or quickly.

What appears to be a joke really is not, and in the ICU described by Zussman, cheechee becomes the habitual word for torture used by both nursing staff and physicians. According to Zussman, staff at his second site employ the term torture less often. Nevertheless, when they do it involves both the idea of inflicting pain and a sense that the treatments that cause the pain are ultimately futile. Zussman concludes that treating incurable patients is not only painful to the patient, but to the staff as well, and consequently torture (or cheechee) refers not only to the suffering of patients, but also to the suffering of doctors and nurses (Zussman 1992:111-113).

The extreme character of the situation

Once a nurse suddenly blurted out "*estamos todas locas aquí eh!*"—we're all crazy here. "How come?" I asked her. What did she mean? "Don't know", she said. "We just are. All crazy here." She then continued with her work preparing the vials of medication on a small tray table outside the patient's room. I was intrigued. "So, crazy to choose to be here", I asked, "or you mean you go crazy afterwards?" She laughed: "I think afterwards. It's a consequence. We lose our references." I thought quite a bit about what this nurse meant by her comments, and in part I believe it has to do with the continued exposure to extreme illness and dependency. Nurses in the ICU "lose their references" with regard to "normal" illness, and become accustomed to, sometimes even jaded in the face of an environment of technicity, minimal interpersonal contact, and a strict logic where patients might die at any time. Personnel working in intensive care become acquainted with the extreme. In the ICU, Réné Leriche's definition of health as "life in the silence of the organs" (Canguilhem 1966: 52) proves remarkably fitting. Here indeed, the health conditions are dire, and the organs speak loudly through alarms, beeps, and ventilator wheezing. Many of the nurses with whom I spoke who had *not* chosen to work in intensive care, and who had accepted the job out of necessity, expressed that this was one of their main objections to their work. Indeed, talking about excess in intensive care is redundant, since intensive care by its very nature is excessive (Perez 2008) In Hospitals South and Central, nurses alternated between patients, so that they would not get too attached, or so that it did not become too hard.

On the other hand, for many, both nurses and physicians, intensive care was a good place to practice holistic nursing or medicine. Of course, nurses and physicians have different things in mind when they say this. For a physician working holistically in intensive care, means working with the *body* as a whole, as opposed to how surgeons or specialists in a particular organ work. When nurses said this, however, it referred to the vocation of nurturing or caring, which they felt they were able to do in the ICU due to the highly dependent nature of their patients. This was a source of pride, evidenced quite clearly in Hospital North when nurses expressed great discontent with an administrative plan to extend the unit and include certain less critical patients to the unit. They did not desire to work with *that category of patients*, they emphasized; they were not *intensive* care.

At times, however, I suspect that the treatment situations are experienced radically differently by patients and by their caretakers, and even their next of kin. This became evident when looking at a "thank you" card posted in the break room of Unit Left in Central hospital. The note was from a former patient of whom I had heard talk several times. It was one of the unit's unequivocal success stories. The patient was a young father in his late 20s. They had been close to "losing him," but the team had "come together," they had "fought," done "all that they could," and the patient survived. It was clear that this had been a great motivation booster for personnel, who seemed invested in the treatment of this patient. Reading his 'thank you' however, was sobering. Whereas his wife's note was happy, cheerful, and full of genuine gratitude, the former patient himself expressed that "I was cold, I was thirsty, you denied me sunlight, and you tied me down. But thanks to you, I am alive". Somehow, despite the treatment having been a complete success, the note seemed to prompt the question "at what cost?"

Defying biomedical logic

Just as some felt the relational aspects were lacking from their jobs and some experienced their work as potentially brutal, for others, dealing with anything other than the physical aspects of illness was quite evidently not something they desired. This was especially noticeable in relation to "difficult" patients—patients especially likely to be the subject of humor or sarcasm. In Mizrahi's book "Getting rid of patients" (1986) categories of "worthy" and "less worthy" patients are made. And as a Spanish physician in the ICU put it—in the health care system in general, certain lifestyles "*se castigan*"—you are punished for it.

One such feature is weight. Halvorsen describes in her doctoral dissertation on the subject of ethical decision making in a Norwegian ICU, how overweight patients could be singled out and be referred to as "fatsos" (2009). Indeed, despite the general tendencies of obesity in the world today, obesity in the medical setting appears to be highly disfavored and stigmatized. Once, I saw how staff would crowd the room of a severely overweight patient for no other reason than to *see* him, commenting that, had he not been so big his injuries would have been less severe. It is also frequently commented on, often with humorous overtones, such as one nurse entering a room exclaiming "que de gros bébés!"—what a bunch of big (fat) babies. As such, she was not only commenting on their weight in itself, but likened the obese to children, denying the "fat person" rational agency—which is congruent with observations of judgments of overweight persons as being lazy, unclean, and lacking control of their lives (Wear et al. 2006).

More severely however, patients with additional diagnosis of mental illness, such as bi-polar disorder, schizophrenia, or chronic severe depression, were quite clearly viewed in a negative light. As will have become clear at this point, the ICU is a quintessentially somatic hospital unit. Nevertheless, during my time observing in the clinics, there were many patients whose problems could not be reduced to the purely somatic, such as the patient in Hospital North who, according to his physician looked like a healthy young man "except in his head, of course." In the case of the mentally ill, their disease defies the biomedical logic of the ICU. Moreover, they were sometimes ungrateful for their treatment, and behaved in ways that our society perceives as irrational. There was often a shift in attitude with regard to this category of patients. They were considered *more difficult to care for*, and staff expressed that they were not trained to deal with their needs. Once, I was in a section of Central Hospital's ICU Right, relaxing with some nurses and nurse's aides. All the rooms were occupied, and a colleague from another section came by and expressed sympathy for how much work that they had. "No, not really" one of the nurses answered. Most of the patients were there due to suicide attempts, and thus did not suffer from complex (physical) medical conditions. "All we've got is the relational" he explained. Indeed, this was not really considered work at all. Oftentimes, as discussed in Article 1, the personhood of mentally ill patients was undone by practice. Their disease spoke louder than they did, expressions of their preferences or desires were easily attributed to the disease rather to their person, and more easily ignored. In general, I found that humor or sarcasm at the expense of patients reflected not an attitude of superiority over patients per se, but referring to their social standing outside of the hospital.

Technologies in treatment and in death: securing or alienating?

Once, during a staff meeting, the team in ICU Right at Central Hospital was discussing whether the nephew of a patient should be permitted to visit. Incredulous, one of the doctors blurted out: "What? Come in here and see her with a tube in her throat and all those machines? He'll be traumatized!"

We have seen in some detail, how technology and the pervasiveness of machinery in the ICU are features of contemporary biomedicine in general, and intensive care in particular, that arouse skepticism and criticism. Moreover, as I hope has become clear from the description of the patient's space or room in the ICU, technology is indeed a highly visible, important, and determining part of intensive care. It clearly affects those from the outside who enter the units, not least next of kin. Indeed, in Spain and France, children were not allowed to visit patients in the clinics as it was assumed that it would be overwhelming and, as in the above quote, traumatizing. Indeed, adult next of kin sometimes have difficulties coming to visit because the technicity and severity of the situation is too intimidating, and are encouraged not to enter the room alone.

There is however another side to this as well: to the contemporary Westerner, technology is perhaps more than anything else, comforting. As an experienced nurse expressed, next of kin often *want* to talk about numbers and objective test results. Some visitors seem to see only the monitors, and occupy themselves mainly with attempting to understand the shifting curves and beeps, rather than looking at their loved one. As long as the graphs are still moving, the numbers on the screen stay within a set range, everything keeps to a set rhythm—things appear stable and perhaps even manageable. In a world where the human body is perceived as manageable, what could be more securing than a place filled with machines and monitors? Indeed, sometimes, nurses told me, next of kin believed that as soon as the patient arrived in the ICU, everything was 'fine.' The fact of being monitored to this extreme level signified management, control, and being *saved*.

This must be seen as the reason behind Hospital South's insistence, expressed already in the information pamphlet provided to next of kin that even patients who appear to be doing well are in a critical state, which may deteriorate at any moment. It befalls the personnel, nurses especially, to draw next of kin's attention away from the machinery and to the *human being in the bed*—especially in situations where the patient is facing end of life.

Dying reanimated

> We know that it's a part of reality, and it's supposed to be so. Because (…) patients are very ill and then… We know that some of them are going to die. We have the possibility to technically continue their lives, but that would be going against nature. When everything points in the wrong direction, you have a duty to assure a natural development. (Norwegian ICU physician)

As I have mentioned earlier, European ICUs typically have a mortality rate of around 20%. Out of this, anywhere from 25 to 75 % of deaths follow from non-treatment decisions. There is thus a large difference in the frequency of such decisions. Oftentimes, as Kaufman writes, "the line between some ideal notion of humane end-of-life care and aggressive medical intervention that delays death is not clear to physicians in practice" (2005: 39). Moreover, despite the symbolic weight placed on patient and family autonomy, medical decisions are in reality constrained by the system itself, such as hospital rules, reimbursement mechanisms, and standards of care (2005). With the exception of the financial motif, Kaufman's observations correspond uncannily well to my findings in the clinics. Reaching a non-treatment decision proves difficult and is sometimes drawn-out in practice. In Europe, the medical team, not next of kin, reaches the decision. This is perceived not as a feature of paternalism, but as sparing next of kin from having to bear such responsibility. However, in my experience, physicians prefer that next of kin agree with the decision. In situations where they do not, the team will take more time, during which treatment continues as before. In article 3, I analyze in more detail the ways in which NTDs may develop in the clinic.

The art of a natural death

"The pervasive quest for an emotionally satisfying death," Kaufman writes, "exists uneasily with the fact that dying has become a technical endeavor, a negotiated decision and a murky matter biologically" (Kaufman 2005: 30). According to Kaufman, modern hospitals are not structured to provide the kind of death that people want (2005: 29). Thus, achieving a good death in the ICU is an art. The attitudes of the personnel reflect an idea that given the medical surroundings, death cannot be fully natural in the ICU. This is connected both to the medical intervention and to that of apparatus and medication. Nevertheless, nature or *naturality* becomes something to be achieved, and when it is possible, personnel will undertake a range of actions in order to promote or to bring about an acceptable death, that is, a death that is *as natural as possible*. Indeed, I found that more often than not, the ideals of dignity coincided or crossed paths with the idea of natural death. In Articles 2, 3, and 4, I describe the clear desire on the part of the staff for death to be natural and dignified. In doing so, technology plays and important yet paradoxical role.

On the one hand, technologies of anesthesia, sedation, and symptom control—palliative care—is an important part of ensuring a good death. Indeed, as a Spanish nurse put it; "the end of life is a nasty business." And, ideals of contemporary good, dignified death include that it be hygienic (La Marne 2005: 92). On the other hand, however, technology as far as it is visible, is considered an explicit hindrance to this end and must be physically removed. I believe we might understand this attitude as a *thingification* of technology. Thingification is the process through which *objects* are recast as *things*. Contrary to objects, *things* is a category reserved for the ambiguous, unnamable and potentially dangerous. According to Brown, "we begin to confront the thingness of objects when they stop working for us" (2001: 4). When objects become things, Brown asserts, this alters in fact not the objects/things themselves. Rather, it denotes a particular relationship between the human subject and the object/thing.

When a patient dies unexpectedly, it stands to reason that no preparations are made, and next of kin is likely not present. The acute and unstable condition of many ICU patients means that this may in fact take place at any time, especially during routine procedures, which led a Spanish physician to jokingly refer to hygienic routines as "manslaughter" (homicidio involuntario), or "murderous" (las higienes matadoras). When a non-treatment decision is made however, this allows for preparation. Next of kin are offered time to get to the hospital. As such, it could take more than a day between the decision being made and the event, taking place—during which time the patient would be cared for as before—in order to allow for relatives from other places to be present and for there to be some ritual surrounding the event. This type of death was more frequently perceived by members of staff to allow for *nature to take its course*. Interestingly, we may note that whereas human nature has become cultural through medical science and artifice, an equally important, metaphysical "course of nature" becomes a cultural project. This is dealt with in greater detail in Article 4.

When patients for one reason or another have no next of kin, however, the ceremonious character of death corresponds better to the scenarios of the critics. Both in Norway and in Spain, my ethnographic observations included the deaths of two patients that took place unceremoniously. In both cases, physicians and next of kin agreed upon the withdrawal of treatment. The latter were given the opportunity to be present, and in both cases declined the offer. In one of these, the patient had been severely ill for weeks and the family, who lived far away, had already said their goodbyes in an earlier visit. In the other case, an accident had occurred unexpectedly, and the patient had no chance of survival. Nevertheless, with the consent of her family, she had been kept on life-support awaiting full encephalic death (brain death), with the objective of organ donation. This, however, turned into a quintessential ICU dilemma, as the physician told me somewhat frustrated: "Now she doesn't die." Thus without hope of the patient's condition improving at all, organ sustaining technologies nevertheless prevented her death. Not long thereafter, next of kin expressed feeling uncomfortable with the wait, and asked that treatment be withdrawn. Their reluctance to be present during the death could be due to having already considered their family member as deceased, a tendency also outlined by Seymour (2001).

Despite the patient in this case having minimal brain activity, the patient was given both morphine and sedatives. When questioned about this, the physician explained that indeed, they did not expect by any measure that the patient was able to feel anything. Yet an acceptable and dignified death meant also assuring that the nurse (and others who were present, in cases where this applied) felt comfortable. The doctor stated that they gave the nurses a *long leash* and the "freedom to give the patient whatever she sees fit." No discernible ritual took place in the unit in connection with these two solitary deaths, which might of course prompt us to question where exactly the value of a human being lies in our cultures: within herself, or in her social networks? Moreover, when critics fear technologized and hospitalized dying will be hermeneutically vacuous and depersonalized, are they arguing from the point of view of the patient themselves, or from the point of view of the onlookers and next of kin?

Concluding remarks to the synthesis

My ethnographical study of three European adult intensive care units revealed highly standardized, very similar fields, where the only remarkable difference between sites—omitting medical, pharmacological differences that I am untrained to evaluate—lay in the work culture and in the approach to outsiders such as myself. An ethos of life lies at the core of intensive care, and in the ICU one goes to great lengths to save the patient's life, while the outcome of treatment is always uncertain. In its mundane, day-to-day realities, however intensive care is seldom overtly heroic and the extreme cases are just that, and they are consequently rare. Intensive care is ripe with ethical and existential issues, yet they usually take shape not of grand dilemmas, but of small, sometimes silent or implicit, real-time evaluations and decisions. In this work I have tried to bring forth some of these, both as they pertain to life in the ICU, to end of life, and to dying.

This thesis shows that in practice, there is a multiplicity of ways in which categories of personhood, of dignity, and of nature, are enacted. It deals with a space of tensions between the human, the individual, and the emotional and the automatic, the objectified, and the technical. The ways in which caregiving and treatment is organized, and how it is carried out in practice, reveals much about the values of a given society. Care and treatment, as well as the opinions of those who provide it, mirror what is regarded as being human, having a life worth living—and conversely, of lives deemed unworthy.

More than anything else, treatment in intensive care involves the utilization of sophisticated technology, which has prompted criticism. In particular, researchers in the social sciences, as well in nursing science, appear highly skeptical of the technologically pervasive character of such units, expressing concerns of technological determinism and of machines outshining the human aspects of medical and nursing practice. There is a fear that technologies will rob us of something and exchange authenticity with artifice. Technologies suppress individuality, sometimes lead to unwanted conditions of survival, and produce conditions of death that defy common sense, and that lack, in the opinions of many, ritual and meaning. Personnel working in intensive care at times clearly feel quite ill at ease with their own practice, and there is a real sense of Frank's "embodied paranoia" (1995) both in general society, but also from within, when nurses in the ICU state with clarity that they would *not* want to end up in intensive care themselves. On the other hand, Levinas' calling to responsibility faced with the vulnerable other, on many occasions seems to take place in these sites. I once found myself with a physician and a nurse in Hospital North, who were treating a severely injured and critical patient. "He's looking at at least six months in the ICU", the physician said. "Yeah", the nurse chimed in. "If he even makes it." The physician was unfazed: "He'll wake up in time for the strawberry season." Again, the nurse interrupted questioningly and with a lowered voice; "Sure, but what are the odds*, really*?" Depending on the results of tests to be carried out that afternoon, the doctor estimated that the patient had a 50/50 chance of surviving at all. Yes, the odds were not great, and the recovery would be arduous, the physician agreed. "But can you imagine the strawberries? Waking up after six months and getting a taste of that? I bet you that first strawberry is going to taste damned good!" In the assured touch, the attentive gaze, and fuss over what to do, how to fix things, intensive care professionals are not simply solving a scientific puzzle. They are enacting a concern for their patients, where the focus is on the little things, rather than on the grand.

There is indeed an implicit sense of determinism in intensive care. As long as one can do, one does. As long as one has the capacity intervene, one intervenes. However, it is not so much the technology as the underlying ideology that directs these practices. Indeed, as the goal of medicine is perceived as unequivocally good, this causes a conflation between is and ought, between what we can do and what we ought to do. Nevertheless, without these options, many conditions that we successfully treat today would be fatal. In my experience, there is nothing necessarily void of values, care, and humanity in these care-situations. Similarly, in his analysis of sudden death, Timmermans concludes, death would oftentimes prove (more) senseless to our modern Western sensibilities were we *not* to attempt resuscitation (1998: 162 my emphasis). In this sense, having attempted to save the patient's life provides the next of kin with more comfort.

Intensive care is an *ethos of life*-success story and a testimony, not primarily to the genius of engineering, but to the human desire to prolong life and stave off death.

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Article 1:

Silent Subjects, loud diseases. Enactment of personhood in intensive care. *HEALTH: an interdisciplinary journal for the social study of health, illness and medicine* 20(2): 127-142

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Silent subjects, loud diseases: Enactment of personhood in intensive care

Gitte Hanssen Koksvik
Norwegian University of Science and Technology (NTNU), Norway

Abstract

The topic of this article is personhood in the case of verbally inexpressive, typically unconscious patients or patients with a low level of lucidity. My aim is to show how personhood is done and undone in a close-knit network of personnel, patients, disease, technology, and treatment, borrowing the concept of enactment as developed by Annemarie Mol. The empirical data are based on grounded ethnographic fieldwork conducted in three separate intensive care units in three European countries: Spain, Norway, and France in the spring of 2014. Four weeks were spent at each site. The method used was participant observations and semi-structured interviews with 24 intensive care unit staff members (9 doctors, 12 nurses, and 3 nurses' aides).

Keywords

enactment, intensive care, intensive care unit, medical technology, personhood

The traditional Western category of the person is based on there being a conscious and self-aware individual who experiences herself and the world around her, and who possesses agency (Scheper-Hughes and Lock, 1987: 14). Significantly, identity and personhood often appear to be interchangeable concepts. However, over the last few decades, the category of the person has continued to change and broaden, not least through ethnographic research, much of which has been undertaken in areas connected with health and illness. Indeed, the development of new technologies and advances in the medical sciences, as well as the options presented to us on account of these developments, create new dilemmas that force us to reconsider previously accepted notions.

Corresponding author:
Gitte Hanssen Koksvik, Department of Social Anthropology, Norwegian University of Science and Technology (NTNU), 7491 Trondheim, Norway.
Email: gitte.koksvik@svt.ntnu.no

Medical technologies associated with intensive care, such as artificial ventilation and technologies supplying organ function (for instance dialysis), have allowed for a patient's body to remain "alive" although the brain has ceased to function, hence shifting the criterion of death from respiratory failure and cardiac arrest to brain death, removing death from the realm of the intuitive. This also enables the transplantation of organs from legally deceased individuals whose bodies are nevertheless functioning (Lock, 2002; Sharp, 2006; Zussman, 1992). As for the recipient of such donated organs, life span and quality may be significantly increased, although at a cost of lifelong dependency upon immunosuppressant medication and possible feelings of bodily estrangement due to new hybrid bodies. Such intensive care–related medical advances have also created states of survival that challenge and defy our traditional ways of conceiving both life and death, such as various states of coma or persistent vegetative state (PVS), the latter often being thought of as "a fate worse than death" (Jennett, 2002). Varying slightly from that of being in a deep coma, sufferers of PVS may have periods of open eyes, and they may be roused from sleep by vigorous stimulation. There has been debate about what exactly patients suffering from PVS may or may not experience. However, there is no evidence of a working mind either receiving or projecting information, and there is dissociation between arousal and awareness (Jennett, 2002: 8–9, 19). Reproductive technologies, in vitro fertilization, and surrogacy are yet another ensemble of practices that ethnographic research has proven to challenge the Western dichotomy between nature and culture (Kaufman, 2000; Lupton, 2012; Tellman, 2003). Therefore, it seems logical to explore such issues in the context of a technologically based medical environment. The focus of this article is the notion of personhood in the intensive care unit (ICU), and more specifically in those patients who lack traditional capacities of expression. By this, I mean powers to express oneself in a coherent manner either verbally or in writing. The empirical data stems from ethnographic fieldwork conducted in ICUs in three European countries: Spain, Norway, and France. While stationed at the ICUs, I employed the approach of participant observation. Dressed in scrubs, I followed, observed the ICUs' daily routines, and interacted with both medical and nursing staff. In addition, I carried out semi-directive interviews with approximately 10 staff members at each location.

Biomedicine and reductionism

Biomedicine is based upon a heavily dichotomous understanding of humanity where the seat of a human being is located in our rationality and where the flesh holds only a peripheral importance as a mere vessel for life. This Cartesian view of the body allowed for experimental testing on human beings, both dead and alive. At the beginning of this practice, studying disease in corpses was something rather revolutionary. By doing so, both the disease and the dead human body were objectified and turned into tangible and separate entities. As Drew Leder (1984) explains, "Since the machine-body is extrinsic to the essential self it can and must be entered, studied, tampered with in order to be repaired" (p. 30). This reductionism gave rise to what Foucault (1964) aptly named "the clinical gaze."

Perhaps unsurprisingly, biomedicine has received criticism for expropriation of health and for reducing human beings to body parts or organs, especially from current phenomenological and existentialist theories, which have brought about new concepts of the "lived-body" and of human existence as fundamentally embodied and unified. Prominent examples of this include Ivan Illich's (1976) "Medical nemesis: The expropriation of health" and Manuel Cassells' (1993) "The sorcerer's broom: Medicine's rampant technology." Furthermore, medical technology often comes with negative connotations. This is particularly evident in the literature dealing with modern forms of dying, as well as in the death with dignity debate, where technology would appear to be a hindrance to a humane and good death (Ariès, 1975; Le Breton, 2004, 2011; Leder, 1984; Lock, 2002; Pfaffenberger, 1992; Seymour, 1999, 2001; Timmermans and Berg, 2003). Hence, new anti-paternalist and more individual-centered concepts have contributed to orienting health care in a new direction, where the body is no longer regarded as a passive, imper-sonal object (e.g. Csordas, 1990). However, this places intensive care in a rather awk-ward position, as it remains, arguably, one of the most extensively techno-scientific clinical units of the modern hospital.

To be sure, it could be argued—and I believe rightly so—that any domain of biomedicine or of the modern clinical setting today is highly technological. Indeed, is the person living with a pacemaker not equally dependent upon medical technology for their survival as the ICU patient? And is this not also the case for the in-patient at the oncology unit, receiving chemotherapy and radiation treatment? Nevertheless, one of the crucial differences of the ICU, which I believe distinguishes it from other units such as the oncology unit, is the *pervasiveness* of technologies. As Nancy Kentish-Barnes (2008) writes, "In the ICU, the patient becomes a body whose organs must be maintained, and this body in turn disappears behind the machines" (pp. 70, 77, 100ff).

A practice where anything and everything is possible?

Embedded in the biomedical paradigm, intensive care is a recent branch of high-tech medicine, beginning with the development of artificial ventilator technology in the 1950s. Artificial ventilation enabled life-sustaining treatment of patients with severe respiratory problems, and intensive care has since come to revolve around organ supplying techniques of all vital organs. It is considered as a curative field of medicine, with its main goal being to stabilize organic functions and to provide critical patients with emergency treatment. The French term for this specialization, *réanimation*, from the Latin "return of life" (re—again, anima—soul), is revealing of this particular feature. Patients, who would otherwise die, may be given a second chance at survival through intensive intervention in an ICU. As Perez (2008) claims, "Anything and everything is possible in intensive care" (p. 55).[1]

The typical ICU patient has suffered either extensive trauma (often following traffic accidents, failed suicide attempts, or accidents in the home), or they suffer from grave illness, typically with multiple comorbidities (chronically obstructive respiratory problems, advanced stages of cancer, or internal hemorrhaging). Due to the severe nature of many of the patients' diseases or injuries, ICUs typically have a high mortality rate, and many authors have written extensively on the ethical dilemmas surrounding life-sustaining treatment and the potential withdrawing of such (Halvorsen, 2009; Seymour, 2001). Research suggests that approximately one out of four deaths in ICUs follows from a decision to withhold or withdraw treatment. Consequently, a significant part of intensive care is in fact dedicated to palliative efforts (Klepstad and Gisvold, 2003), contrasting the typical image of ICU as being solely dedicated to curative practice.

As previously suggested, the conditions of an average ICU hospitalization often breach some of the conventional understandings of the conditions under which modern medicine should be conducted. Ideals such as patient autonomy, informed consent, and envisioning treatment as a dialogue or a relationship between equals are rarely upheld. Indeed, in the ICU, the relationship between patient-as-object and patient-as-subject remains a fine, and oftentimes blurry line to maneuver. First, due to the critical and acute somatic nature of the patients' situations, emergency life-saving measures require an urgency that leaves little or no room for conversation. Many patients also enter the ICU in an unconscious state, for instance, following surgery. In order to save the life of the patient, therefore, an objectifying look at specific organic functions, mechanisms of respiration, blood gas results, and other laboratory results are crucial. Above all else, the stabilization of vital functions is this particular branch of medicine's expressed goal.

While in the clinic in France, one of the physicians asked me to specify my exact research interest. I answered that I wish to look more closely at the personnel's approach to their work, including their interactions among themselves and toward the patients. Having said this, an intern shot me a rather baffled look and grunted humorously, "Well, there isn't really that much interaction, 'cause you know, they're asleep, right? I mean, you say 'hi' when you enter, but you don't expect a reply!" This intern's reaction was revealing. Indeed, what kind of interaction can there possibly be with someone who is unconscious or, as it is more commonly put, asleep? Yet, if this is not an interaction, why bother at all to say "hi" to someone who is not in measure to reply, and perhaps not even to hear the greeting? Such ambiguities fill the spaces of the ICU and its practices.

Finding a suitable approach

During my research, I frequently asked medical staff why they chose to work in intensive care. To this, doctors sometimes expressed their desire to "work with the patient in their entirety," as opposed to fields that focus on a particular organ. Many also appreciated being able to see quick results of their interventions. Indeed, the intensive care physician obtains immediate results of the adrenaline she administers, of a change in posture of the patient, and so on, as opposed to, for instance, the general practitioner who may prescribe a drug with instructions to "come back in a week." Treating a patient in the ICU may take the form of solving a puzzle: calculating dosages, trying to find out the right combinations, taking into account all facets of the patient—organic functions, respiration, blood levels, brain activity, and so on. However, these are all objective measures. Thus, when doctors use expressions such as "the patient in his entirety," what they really mean is the patient's *physiology* in its entirety.

Many of my informants in the ICUs, including both doctors and nurses, relayed a keen interest in the mechanical aspects of their work. More than a few—particularly nurses—also appreciated the limited verbal interaction with the patients and had chosen the ICU for this reason. This finding corresponds with Zussman's study conducted in the

United States in the late 1980s, in which he concluded that ICU nurses won the respect of physicians through technical skills rather than emotional qualities, and that knowing the patients first of all referred to having knowledge of their anatomy and pathology. Both nurses and physicians, he claimed, had become technicians (Zussman, 1992: 70–72, 79–80).

Paradoxically then, nurses at my field sites often pointed out how they liked to talk with patients, get to know them, offer encouragement, and try to lift their spirits. Not surprisingly, this applied even more so in the case of patients who were lucid and communicative. Nevertheless, my experience from the field is that such interactions are brief. For wake patients, a substantial amount of time is spent staring at a wall or watching TV where one is available. In particular, both the nursing and medical staff at the unit in France regularly commented that the emotional and psychological aspects of treatment were not being sufficiently addressed. Yet, immediately after, they would remark that they were not in fact trained to care for the psychological or emotional needs of the patients, implying that although this was something they believed was lacking, they were incapable of remedying the situation.

There is generally rather little regard for patient values and the patient's personality in the ICU, which follows in part from patients being unconscious. Indeed, oftentimes, treatment is conducted on presumed consent. Furthermore, in cases where a patient refuses a particular treatment, this may be administered regardless, particularly if the patient is considered to be confused or disoriented—something that occurs frequently. However, I did not find that the ICU staff was exclusively focused on the application of technical skills. Particularly among the nursing staff, the sense of personal fulfillment obtained from being able to care for a completely helpless individual and attending to their every need stood out. Many of my informants did indeed emphasize the importance of the non-mechanical aspects of their jobs, such as talking with their patients and touching them, just as much as the technical aspects of their jobs. Furthermore, doctors often expressly valued the interaction with and information obtained from the next of kin, and many said they derived great satisfaction from being able to help guide families through a difficult time and were excited when former patients came back to see them.

Social anthropologist, Bryan Pfaffenberger (1992), has exposed what he calls "the standard view of technology." According to Pfaffenberger, the standard view of technology posits that the first simple technologies were born out of humans' need to control their environments. As their needs were met, more sophisticated technologies could be construed, still filling the needs of humanity by allowing us to live better. At some point, however, technology seemed to have gained momentum and an upper hand on humanity, henceforth developing at an uncontrollable speed. When it is no longer humanity's tool, technology becomes a dehumanizing force and a threat. The rupture is to have occurred between the use of tools, which are under human control and thus represent authenticity, and the development of machines, which are too big and too autonomous to be authentic. This position is otherwise known as technological determinism, and it is certainly the view reflected in Cassell's (1993) "The sorcerer's broom: On medicine's rampant technology." On the other hand, the social essentialist would still regard technology as a blank slate, as something that is value-neutral, created and controlled by humans, which may only receive meaning through its cultural use and insertion (Timmermans and Berg, 2003). Either way, according to both essentialist and determinist views, culture and nature remain on their respective sides of the gap. The difference is simply about which one drives the other.

I believe that such interpretations are ill suited for exploring contemporary medical realities, as medical technology is certainly not value-neutral, yet nor is it running the show at the expense of humanity. Therefore, I would like to employ the word technology in a broad sense. Timmermans and Berg (2003) identify what they call "technology-in-practice," which includes "the entire gamut of mundane to sophisticated technologies, drugs and even managerial instruments such as patient records" (p. 104). This approach echoes actor–network theory (ANT). According to ANT, machines, architecture, clothes, and texts—to mention just a few artifacts—all contribute to the patterning of the social. What is more, rather than seeing either nature or culture as the determinant part of reality that drives the other, authors adopting the ANT view consider this to be context dependent. Consequently, both humans and inert objects may acquire active agency (Latour, 1997; Law, 1992). Furthermore, we also see that people working at ICUs sometimes display incoherent—or at least seemingly incoherent—opinions concerning their work, which calls for a more nuanced approach.

In Annemarie Mol's (2002) book *The Body Multiple: Ontology in Medical Practice*, she describes and analyzes the workings of a Dutch university hospital showing how the body and disease, in this case arteriosclerosis, is "done" through a variety of practices. These "doings" include persons, artifacts, speech-acts, physical action, technological intervention, and objects. Mol suggests that this illustrates a move away from epistemology to the ontology of medical practice. Instead of being primarily concerned with the accuracy of one's representation of reality—a reality thus assumed to be singular, the focus becomes on the multiple ways in which reality is indeed enacted.

As such, ontology is not given in the order of things, but ontologies, rather, in the plural are "brought into being, sustained, or allowed flourish in day-to-day, socio-material practices" (Mol, 2002: 6). According to Mol (2002), her book "tells that no object, no body, no disease, is singular. If it is not removed from the practices that sustain it, reality is multiple" (p. 6). Opting for the term "enactment" rather than "construction" or "representation" otherwise well known in social science, Mol explicitly avoids seeing this bringing to being as a necessarily conscious or political. This approach also rejects Goffmanesque (1959) theories of front stage and back stage, according to which there is a conscious presentation outwards and a more genuine reality or identity underneath, reserved for privileged access "back stage." By using "enactment," the world as we know it comes into being through action, and this is the result of an intricate network. "In practice" Mol (2002) writes, "the body and its diseases are more than one, but this does not mean that they are fragmented into being many" (preface, p. viii).

Like ANT, Mol's perspective also wishes to challenge the classical divide between acting subjects and acted-upon objects, between subjects as knowing and objects as known. In this light, Foucault's (1964) characteristic of modern medicine as a discipline where humans are for the first time both the subject and the object takes on a new, richer, and no longer dichotomous meaning. Pushing a step further, enactment theory also maintains a fluidity between humans and objects, so that the dichotomous understanding of subjects-as-humans and objects-as-nature no longer holds. Simply put, in light of enactment theory, things of all sorts can be analyzed as relational qualities and beings that are contingent upon their environments. Anyone and anything may be an actor, just as much as it may be acted upon.

A possible difficulty with employing this approach is Mol's focus on the enactment of objects. Personhood is not a tangible object, and as previously mentioned, both the boundaries and the content of the category vary. As such, one could indeed say that personhood *is* nothing in itself. How then does enactment apply? Can there be an ontology, multiple or otherwise, of something that is admittedly contingent? In anticipation of such critique, I nevertheless feel the approach is suitable due to the following reasons. First, the enactment perspective is fruitful for the very reason that it acknowledges ambiguity and even internal incoherence in the ways in which something is brought into being. Second, it favors a distinctly fluid approach to agency, which is useful in the context of intensive care.

Another issue is that of power struggles. Mol's approach pays little attention to the many power struggles and political issues that may be involved in how objects and truths are brought about—which ones are accepted and allowed to flourish and which perspectives disappear. I believe that normative assumptions do play a part in the enactment of personhood in the ICU, and these necessarily relate to societal and individual values, and are therefore contested.

Enacting what exactly?

As stated in the introduction, the traditional Western category of the person is based on there being a conscious and self-aware individual who experiences herself and the world around her, and who possesses agency. This, I believe, has its basis in classical (Western) philosophical literature, such as the writings of 17th-century empiricist, John Locke. According to Locke, a person is a thinking and intelligent being. Furthermore, he posited, a person is able to consider itself as itself and have a continuous understanding of individual identity over time and in different places (Locke, 1997). Nevertheless, anthropological research has done much to expose the cultural relativity of the notion of personhood, by showing how different cultures and societies operate with different categories and conceive of them in multiple ways. In many non-Western societies, personhood is described as being above all a relational quality or a process (Conklin and Morgan, 1996: 666). In his text on the categories of person and individual, J.S. LaFontaine (1985) points out how, in some African societies studied by classic ethnographers, namely, the Tallensi of Ghana and the Taita of Kenya, only select individuals may hope to achieve full personhood. The self and the person are here considered as distinct qualities, the latter being awarded only to some members of society as the result of a lengthy process, running sometimes over the course of an individual's entire life (LaFontaine, 1985: 135–136). As such, personhood must be earned. In some cases, it may also be lost, as Conklin and Morgan (1996) comment, "The accrual of personhood is not necessarily a one-way process; under certain conditions, personhood may be lost, attenuated, withdrawn or denied" (p. 667).

In "'Animism' revisited," Nurit Bird-David (1999) writes that in the culture of the Nayaka in South India, persons are not considered as *in*dividuals but rather as "dividuals" (p. 72). For this analysis, she draws upon the work of Marylin Strathern (1988) in Melanesia. Strathern (1988) argued that the irreducibility of the individual as a single entity is a modernist notion, and that the Melanesian "person" is a composite of relationships—a microcosm even, of society as a whole (p. 13,131). The dividual, that is, humans in relation to others, is emergent and is constituted by relationships that are worked out in a range of social processes (Bird-David, 1999: 73).

To be sure, showing how personhood takes on different qualifications and meanings across cultures does not in itself inform what it means to look at personhood in the context of the ICU, when the ICUs studied are indeed all located in what can only be called a Western setting. Nevertheless, I suggest that in the practiced reality of "local-moral worlds," to borrow the words of Arthur Kleinman (1999), reality takes on different forms, even within a so-called Western context. Not least in light of, as has been mentioned, the challenges to our accepted truths and categories brought about through the advances in medical treatment and technologies.

To wit, research on sufferers of PVS exposes a complex reality. Conducting research in a specialized treatment facility for patients in a PVS in the United States, Martha Kaufman argues that the personhood of the patients does not disappear. Despite the loss of self and any form of autonomy, which would seem to inhibit the existence of any Western notions of personhood, she shows how personhood in these patients persists as a negotiation through inter-subjective knowledge. Through staff and more importantly next-of-kin's moral and emotional attachment to the patients, as well as through the memories of their past existence, "life" is maintained. Conducting a similarly themed research on PVS in Israel, Nurit Bird-David and Tal Israeli underscore that personhood in such conditions is not only relational but also situational, and as such, contingent, malleable, and changeable. It may disappear and reappear, they argue, depending on the situation—hence the title of their article: "A moment dead, a moment alive" (Bird-David and Israeli, 2010). Their findings suggest that during one simple interaction, such as a morning hygiene routine, the approach to the patient may vary from one caretaker to another, and also in the attitude of the same caretaker. Nurses may shift from talking to the patient and engaging in a one-sided conversation to discussing the patient with a colleague as if she were absent, or talking about unrelated issues of their own lives and paying seemingly little attention to the patient. Furthermore, and quite interestingly, Bird-David and Israeli (2010) emphasize the importance of moral judgment. Interpretation and valorization of the patient's former life and the context of their accident or illness plays a role in the mediation of personhood. Even a patient's immune system and subsequent propensity for infections may be bestowed upon them as qualities or personality traits. In the example, the authors refer to a "bad patient": a woman who is considered to be overall bothersome, in part due to her propensity to contract infections (Bird-David and Israeli, 2010: 60–61).

Below, I present two cases from my ethnographic studies of everyday practice in the ICU. The first is a typical routine occurrence with what I have chosen to call a "standard" patient. The second is quite different, relaying incidents from the treatment of a noncollaborative patient that I have chosen to designate as “deviating.” Changes have been made in both cases to ensure the anonymity of all of those involved.

Case 1. The standard patient: “Good morning, Mr Smith”

It is early morning and the sun shines a cold light through the windows on the far end of the otherwise dark, single patient room inhabited by Mr Smith. The room looks much like any other room in the ICU; a counter with two separate sinks and a medical equipment storage area lines the wall beneath the windows. Different purpose garbage cans stand on the floor next to the counters. The bed, a tall, large, elaborate contraption, is located in the middle of the room where Mr Smith lays immobile. On either side of the bed are a number of stands holding monitor screens that display his vital signs, blood pressure, oxygen levels, and breathing. Bags of fluids and medication are connected to the patient by a multitude of tubes. This is Mr Smith’s 10th day in intensive care following an acute episode of respiratory distress due to his deteriorating leukemia. On the wall facing the bed hangs a picture of Mr Smith and his family taken before he fell ill. The picture bears very little resemblance to the body lying in the bed. Mr Smith is intubated, and the artificial ventilator makes a shushing sound as it inflates his lungs with oxygen at regular intervals. His body is covered with a white sheet. All nutrition is administered through the tube, and bodily waste is evacuated into two separate bags hanging off the side of the bed, which are emptied at regular intervals.

When entering the room, the nurse switches on the light to signal the start of a new day, and walks over to his head. She presents herself and asks him whether he is in pain; she asks him to blink once if the answer is yes. She then starts preparing the day’s dosages of medication. A nurse’s aide enters, puts on an apron and gloves, and walks over to the patient’s head and repeats the same routine. He calls “Mr Smith” by his name, presents himself, and tells him that he will be the one responsible for the morning routine.

As they begin to wash the limp body, they gradually expose the different body parts, cleaning them with assured and even gestures without looking. They work quietly distributing the tasks among themselves.

An alarm sounds and one of the graphs flashes. They both stop. Neither of them needs to look to know which one it is; they know the alarms by heart. It is the blood pressure. The nurse looks at Mr Smith and asks him whether it hurts. She observes that his brow is frowned and continues talking, reassuring him that they know it is uncomfortable, but that what they are doing is very important. They will be very gentle from now on.

A third person enters as they prepare to turn the patient over on his side to change the sheets and wash his back, a necessary procedure in order to prevent bed sores. They tell “Mr Smith” what is about to happen, and then tip his body over, adjusting the tubes. The work takes a while, and after a while, the nurses start bumping their hips together and joking around. They talk about what they did last night, what they like to watch on TV, ICU gossip, and gush over their latest love interests.

The morning routine is over, and Mr Smith is placed on his back, and covered once again. They tell him that they will leave him in peace now, and once more, the room falls silent, safe of the sound of the ventilator.

Case 2. The deviating patient: "It's only the disease talking"

This patient had been admitted to the ICU after entering a coma due to an overdose. During the last few hours, he had been woken up forcefully by antidotal medication, a supposedly very uncomfortable procedure, yet a necessary evil in these cases. While still in a semi-conscious state, the patient managed to rip out his feeding tube, without which his treatment would be ineffective.

It is around mid-day and the sounds are atrocious. Walking down the broad corridor which is the connecting space of the medical ICU to which three sub-units are attached, I am drawn to the farthest most one, where the sounds seem to originate out of the five available rooms, only three are occupied. Moaning and groaning that give shivers down one's spine emerge from one of the rooms. Several staff members, including two doctors and a few nurses, are crowding the bed, pinning the patient down, trying to position him better as his obese and limp body keeps slouching down in the semi-erected bed. The doctor informs the patient that they will be reinserting the tube now. The patient growls loudly, the alarms are beeping non-stop. The sounds can only be interpreted as a desperate refusal. "Oh, yes, yes, yes," the doctor replies emotionlessly. The patient is pinned down once again and the nasogastric tube is inserted through his nose. The noise persists. A nurse tells him loudly and in a strict tone to "calm down!"

Once the doctor exits the room, I take the opportunity to ask her whether the patient is in pain, as this is what it sounds like to my ears. She answers conclusively that he is not in pain. "It is the disease talking," the doctor explains, as this patient suffers from a mental illness that is taken to be at the root of his suicide attempt. "He is not in pain," she repeats, "he is just manifesting his discontent."

The patient moans again rather noisily, and the nurse tells him once more in a loud and strong tone: "it's sleepy time now!" With a strong movement, she tucks the blanket around him. The nurses exit and reenter quickly with the proper equipment required to tie the patient's hands to the sidebars of the bed preemptively. The patient eventually calms down, and once on the outside of the room, the team regroups. The nurse says jokingly, "See? You have to treat them like they're kids. That's what works!"

As the days passed, the patient alternated between recovery and lucidity, and convulsions that necessitated sedation and re-intubation. The convulsions often made the personnel's work difficult as they were unable to hold the body still, thus endangering the different tubes in catheters being inserted correctly. For this, the patient was loudly reproached. "Participate in the care process, will you?" one nurse said. Once fully awake once more, the patient suffered severe delirium and maintained long conversations with invisible interlocutors. On occasion, however, his tone changed and lucid sounding messages such as asking for something to drink or asking that the door be shut could be heard emerging from the room. I asked a nurse about it, and she replied: "Oh, really? I didn't hear anything."

Individual silence, organic loudness

The two "cases" described are not meant to be comparable; rather, they aim to illustrate different features of the patient–caretaker relationship, and the admission setting in an

ICU. The recount of Mr Smith's morning routine is a representative account of such situations in an adult ICU. Indeed, Mr Smith is a typical ICU patient suffering multiple organ failures; he is intubated and has low-level consciousness. His condition is severe, and his physical appearance has been altered by treatment, which is quite commonplace in the ICU. The picture on the wall, representing him in another setting in the outside world, erected by the next of kin, presents one way of enacting Mr Smith's personhood. It serves as a constant reminder that he exists in a wider social setting outside of the hospital and outside of the role of patient; the picture shows staff what he "really" looks like. As such, it reminds them that Mr Smith is more than "just a body,"—a view held by many of the ICU staff members. Furthermore, a picture on the wall is a sign that the patient has a family of some kind. This is not without importance, as research has showed that staff will often make greater efforts or have more difficulties ending the treatment of a patient whose family makes their presence (and their demands) felt in the unit (Halvorsen, 2009).

In addition, personnel entering the room present themselves, thus engaging in a relationship with the patient. By calling the patient by his name, they recognize his identity, and as we have seen, for Western Europeans, identity and person often appear to be two sides of the same coin. The team informs Mr Smith of what is going to happen, making him a partner in the routine. By being alert to his level of discomfort or pain, the nurse enters into non-verbal communication with the patient allowing for eye flutters, facial expressions, as well as tensing of muscles as expressions of attempting to relay messages to the outside world when they cannot be put into words. The nurses recognize the alarms, which to an outsider sometimes sound more or less the same, and react accordingly.

The deviating patient is all but quiet, yet his utterances are interpreted as having no sense and are blocked by personnel who do not engage with him or his attempts at communication. Indeed, as the doctor tells me, since it is "just the disease talking," the disease becomes more real and tangible than the patient himself. This disease has been accessed by personnel through the patient's file and is not related to his admission in the ICU. This is a perfect example of what Bird-David and Israeli talk about when they notice that moral judgments about other aspects of the patient's life enter into the consideration that staff have for them during care. Of course, a psychiatric diagnosis may indeed be relevant to treatment, yet I believe that it was in this occasion used as a manner of circumscribing the patient's wishes or attempts at contact with his surroundings, as also later, when he explicitly verbalized demands to staff, these were overheard. In this case, a document stating a disease became more of an actor in the situation than the individual patient did. "Clinical patienthood," Mara Buchbinder (2011) writes, "hinges on diagnostic assessments" (p. 457). Writing about chronic pain sufferers, Buchbinder argues that

> To determine that a pain is "real" as opposed to mental, emotional, and "all in your head"—helps to establish that a person is not crazy thus mediates judgments of legitimacy, and bears heavily on the kind of person one is taken to be. (p. 457)

The deviating patient seems to be an example of the opposite, namely, what can happen when a diagnostic assessment of mental illness, or more crudely put, "insanity," has already been made. The diagnosis follows the patient in the form of a notation on a file, and in this case, I believe it is used by staff as a way to enact his personhood as that of "a crazy person" or that of a non-person by being able to ascribe a range of symptoms and utterances as being "the disease."

René Leriche's statement that health is life in the silence of organs has been interpreted as giving value to the embodied experience that illness often brings to the suffering individual (Fraser and Greco, 2005: 20). In the case of sedated patients in an ICU, such as Mr Smith, they may not at all experience their illness in such an embodied manner—at least not reflectively. Nevertheless, their organs are all but silent, lending an interesting truth to Leriche's claim. The lack of human words in an ICU is often replaced by the sounds of organs. The monitored heart, the mechanically controlled lungs, kidneys on dialysis, and pain receptors on analgesic medication—they all converse constantly with the outside environment.

Normally, we consider the skin to be the barrier of the individual. However, in this setting, the machinery emerges not as a replacement of certain functions, nor, as some have claimed (Kentish-Barnes, 2008), as an independent entity, next to which the patient is drowned out. Rather, it is more fruitful to regard machinery as an incorporated, and thus integrated, part of the patient. Indeed, treatment in an ICU is, to a great extent, a network between doctor or nurse, patient, and machinery. For instance, the nursing staff acts upon the patient in a way that triggers a physiological response of pain. This is picked up by the machines, and sets off the alarms. Thus, when the alarm sounds, we see yet another enactment of personhood, as this triggers a response in the nurses, which is interpreted as a direct communication of physical pain or discomfort. As Merleau-Ponty (2014) argues, for the blind man, the cane becomes an integral part of his person; also here, in the case of the standard patient, the machines and tubes could be viewed as a prolongation, playing an essential role in the state of personhood. During fieldwork, I observed how patients with a greater degree of lucidity sometimes deliberately manipulated their electronic devices in order to set off the alarms. This, although a source of much frustration for nursing staff, must be seen as an attempt at communication on the part of the patient. Not only do the machines communicate for the patients, the patients communicate through the machines. When the nurse then turns to the patient in acknowledgement of the communication, the validity of the reaction is established.

In 2009, a French woman named Angèle Lieby suffered a rare illness causing complete paralysis of all the muscles in her body. Believed to be in a deep coma and without hope for improvement, Lieby was nevertheless fully conscious at all times. In Lieby's testimony "Une larme m'a sauvée" (Lieby and Chalendar, 2012),[2] she explains how the fear, pain, and turmoil she experienced finally resulted in a tear rolling from her cheek, which made her daughter insist that she must not be in a coma and could not be disconnected from the ventilator. Her narrative, although not representative of the average ICU patient due to the rare nature of her illness, provides an interesting insight into the lived experience of inexpressiveness. At one point, Lieby writes that while completely paralyzed, her frustration culminated in tachycardia that appeared on the monitors and sounded the alarms. The hospital personnel interpreted this as an objective quality, to which Lieby made the bitter observation: "I have learnt how to scream, but no one is listening" (Lieby and Chalendar, 2012: 63).[3]

However, such machine–patient fusion requires a level of cooperation. This is frequently mentioned in clinics, where some patients are said to "fight the machines" or that "treatment is a struggle between him (the patient) and the machine." This endangers the efficacy of the treatment, such as in the case of the "deviating" patient. Patients often feel the urge, consciously or not, to remove tubes and catheters, and it occurs rather frequently that they attempt to do so, particularly in a wake-up process where they begin to be aware of this disturbing presence, and yet cannot be reasoned with or made to understand its importance. As the procedure is medically necessary and urgent, it is not surprising that the team pay little attention to the patient's refusal. More noteworthy in the case of the "deviating" patient is the nurses' negative attitude toward his lack of bodily composure.

As seen in the research on sufferers from PVS who are kept alive in a social manner due to the next of kin and knowledge of their former lives, the flipside of such embodied medicine is increased responsibility—possibly even blame—for one's physical ailments, as the body becomes what we are and not what we have. In cases when an individual can no longer express themselves, their personhood and status are decided by others—moreover, we see, by the judgments that they exert, on her past and lifestyle, as well as on her mental or physiological qualities. Thus, while objectification is often believed to be a supreme evil in the medical encounter, the reality might be somewhat more nuanced.

The detached manner in which the staff attended to Mr Smith's bodily hygiene, for instance—not looking, uncovering part by part of his body—contributes to "doing" Mr Smith's personhood by maintaining a level of respect for common rules of modesty and bodily integrity that would be in play elsewhere in society. Indeed, the issue of bodily integrity is important in ICU care, albeit not yet equally so in all phases of treatment. Through acts of covering the body of the patient and shielding them from onlookers who might pass by, this is not just a question of vanity or esthetics, but a way to maintain the identity of the patient by protecting them from the violence of exposure and that of losing face. Goffman (2005) emphasizes the importance of grooming and of controlling how we appear in public or social situations, distinguishing a "personal front" where we discipline body parts, clothing, and our face according to the type of situation and expected behavior (pp. 83–85). The deviating patient, on the other hand, makes this difficult, as his body is difficult to maneuver due to its size, his reluctance to treatment, and convulsions. The negative attitude of nursing staff might therefore testify to a failure on his behalf to comply with accepted norms of bodily discipline, of gestures, and sound making. As seen in the second case, at no point was an attempt to soothe or reassure him made, and instructions to calm down were given as loud orders. This may be regarded as a negative enactment of personhood or as the undoing of personhood. Paradoxically then, he is held accountable for his lack of cooperation during seizures, which appears to be a consequence of his obesity and mental illness being interpreted as qualities of his personality—and highly negative qualities at that. Indeed, it appears that in a somatic unit where technological intervention is pervasive and treatment relies heavily on an objectified and organ-centered medical attitude, the patient may still be held accountable for his disease. Consequently, it becomes quite clear how an object—in this case the disease—becomes an actant, and the subject—the patient—is passively acted upon; this shows the relationship as being constantly fluid and inconsistent.

Concluding remarks

Conceptualized as a transitory unit where relational faculties of the patients are usually suppressed, I believe an ICU generally takes on an air of "doing what has to be done," and if treatment is experienced as violent, reductionist, or without regard for the patient as a person; this is conceived as the necessary price to pay. Furthermore, looking at personhood in a reduced state, which is only temporary, may seem less important and certainly less exotic than dealing with individuals suffering such loss of traditional markers of personality on a permanent basis. Yet, as a temporary, technological setting, the ICU may shed light on the topic of personhood as a negotiation between multiple factors that emerge as important when the individual lacks expressive capacities in a situation where personhood is in no way at the center of anyone's attention.

What emerges is a domain in both medicine and nursing, which functions as a constant negotiation of rationalities, of ideals that are difficult to reconcile. An ICU patient constantly risks becoming a piece of furniture as a consequence of unconsciousness or low lucidity. As the personnel cannot converse with the patient, they start talking among themselves. This may be an inversed enactment of personhood, where the attitudes and actions of staff can be seen as negating the personhood of the patient and reinforcing the image of them as inexpressive. This is, of course, exacerbated in the cases where personnel talk about the patient at hand, as if they were not in fact present. Nevertheless, despite the technical empire of intensive care, Cartesian-like dualism proves unfruitful. For an ICU, maneuvering objective and subjective criterion presents a challenge that is handled through constant unconscious mediation.

Both of the interactions I have highlighted as cases above must be seen as ethical interactions mirroring social values and norms. In the standard patient–caretaker interaction, the enactment of personhood remains a balancing act between the recognition of an outside identity in an otherwise limbic space, varying from complete denial and consideration of the patient as an object-at-hand to a genuine engagement with their intentionality. The emerging picture of personhood is complex. It is not something that exists in any objective and detached manner, nor can it be dependent on one quality alone, for example, rational capacity or even being alive. Rather, it exists in the context of a network of relationships that include and engage other people, artifacts, employment of senses, and speech. In my opinion, the example of the "deviating" patient illustrates how certain behaviors, including involuntary or unconscious ones, come to be given a moral value. The illness from which a patient suffers may be enacted as a separate entity and therefore independent of a patient's intentionality or personality; at the same time, it lies at the root of illegitimating the patient's claims and expressions, resulting in the undoing of their personhood.

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Notes

1. My translation.
2. Saved by a Tear.
3. My translation.

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Author biography

Gitte Hanssen Koksvik is a PhD candidate at the Department of Social Anthropology at NTNU. She has an MA in philosophy. Her project is part of the international and interdisciplinary research program Cultural Logic of Facts and Figures (CUFF).

Article 2:

Dignity in Practice: Day-to-Day Life in Intensive Care Units in Western Europe. *Medical Anthropology* 34(6): 517-532

Article 3:

The Microethics of non-treatment decisions. Examples from European Intensive Care. Submitted to *Journal of Medical Ethics*.

Article 4:

Medically timed death as an enactment of good death. An ethnographic study of three European Intensive Care units. Accepted for publishing by *OMEGA. Journal of death and dying*.

Medically timed death as an enactment of good death: An ethnographic study of three European intensive care units.

ABSTRACT

The article is based on ethnographic observation and semi-structured interviews with personnel in three European adult intensive care units. Intensive care is a domain of contemporary biomedicine centered on invasive and intense efforts to save lives in acute, critical conditions. It echoes our culture's values of longevity. Nevertheless, mortality rates are elevated. Many deaths follow from non-treatment decisions. Medicalized dying in technological medical settings are often presented as unnatural, impersonal, and undesirable ways of dying. How does this affect the way in which death is experienced by intensive care professionals? What might the enactment of dying in intensive care reveal about our cultural values of good and bad dying?

INTRODUCTION

The success of modern biomedicine is a testament to modern values, where health and longevity are key features. Everything can, and must be, treated. In the words of Björn Hofmann, "progress in medicine these days seems to extend to death itself" (Hofmann, 2002: 157). Indeed, as Cécile Lafontaine notes, there is an exerted desire to vanquish death by technical means, to live without growing old, and to prolong life indefinitely (2009: 14). In light of modern dying, several authors have argued that death has become unacceptable or devoid of meaning. It has been claimed that by replacing ancient religious rituals with technology, a hermeneutic vacuum has been created (Timmermans, 1998: 146-147). Indeed, the literature associated with the modern 'way' of death oftentimes takes the form of a critique of medicalized, hospitalized death, which is represented as opposite to and threatening an idealized humane and 'natural death' (Dupont, 2007; Kentish-Barnes, 2007: 449). This is perhaps especially visible in technological medical domains, where organ-sustaining treatments allow for a body to be kept alive almost indefinitely. Indeed, domains in which the medical intervention in the process of dying is clearly visible are held up as extreme examples of the metamorphosis of death from 'natural' into 'unnatural' events (Seymour, 1999: 691-692). Influential historian of ideas, Philippe Ariès wrote that modern hospital death was not a ceremonious occasion marked by ritual, but rather a technical phenomenon obtained by the end of treatment, a decision made by medical and hospital staff. As such, death had been "decomposed, pieced into a series of small steps of which it is difficult to know which is in fact the real death" (Ariès, 1975: 63). Moreover, there is a tendency in the literature on technology and death, to assume that technological death facilitates the loss of the dignity of the individual, loss of self-possession and conscious integrity. And that this environment causes depersonalization, psychological mutilation and scars for family members (Timmermans, 1998: 147). As David Wendell Moller wrote: “The social status of the dying person is diminished” and “their worth as human beings becomes less and less important” (Moller 1996: 22).

In the present article, I intend to look into the subject of death in the context of one such domain: the intensive care unit. As a prime example of contemporary high-tech medicine, intensive care in the West is estimated to have an approximate mortality rate of 20% (Nimmo and Singer, 2011). Depending on the source materials, anywhere from 25% to 75% of all deaths follow from so-called non-treatment decisions (Klepstad & Gisvold, 2003; Domingo, Badia, et. al., 2014; Sprung, Cohen, Sjokvist, et al., 2003). Non-treatment decisions (NTD) is a term that comprises any decision where it is judged more beneficent to either not initiate treatment, to withhold further measures, or to withdraw already initiated treatments. In a domain such as intensive care, the critical condition of the patients means that when a non-treatment decision is effectuated, the patient most often dies shortly thereafter. It is indeed, a medically timed death. Furthermore, the continued academic interest in NTD in intensive care testify to a perceived inherent difficulty associated with this practice (e.g., Heland, 2006; Halvorsen, 2008; Azoulay, Chaize and Kentish-Barnes, 2014; Kentish-Barnes, 2009; Schaller and Kessler, 2006; Wilksinson and Savulescu, 2011; Romain and Sprung, 2014; Anspach, 1993; Callahan, 1990; Sprung, Sjokvist, Cohen et al., 2003).

Based on this and on the critical disposition of academic writings on death in high-tech, medicalized settings, one could surely imagine that intensive care personnel find themselves in a difficult position. Indeed, they have to deal with death and end of life on a regular basis, all the while being aware that this is a form of dying that is culturally ill viewed. On the surface, both these facts go against medical ethos to save lives, and to provide good care.

Consequently, when conducting ethnographic studies of three separate intensive care units (ICUs), in France, Norway, and Spain, I was curious to find out more about death in the ICU. In the following article, I shall look into the two typical 'ways of dying' in intensive care: sudden death and death following NTD. As it turns out, despite the apparent ethical difficulties and technical nature of death following NTD, this is often preferred over sudden death. Through examining how foreseeable death is framed, I wish to show how ICU professionals' opinions about death in the clinic relate to cultural notions of good and bad death.

METHODS

The article draws on my own ethnographic materials. I spent three weeks in a Norwegian intensive care unit in early 2012, as well as month long stays in Norwegian, Spanish, and French intensive care units during the spring of 2014. All three units were urban, university teaching hospitals. The ICUs were multi-purpose, adult units, each holding between 10 and 15 patients at any given time. In the units, I adopted the approach of participant observation, shadowing both medical and nursing staff in their daily routines, as well as sitting in on meetings, rounds, and occasionally being present in information meetings with next of kin. In addition, I conducted semi-structured interviews with 24 members of staff, 9 physicians, 12 nurses and 3 nurse's aides. The interviews as well as conversations within the clinics were conducted in the language of the respective location. The interviews have been transcribed and translated into English by the author. As the empirical data stems from European countries, I have limited the literature concerning guidelines or laws to the same geographical area.

INTENSIVE CARE AND "REANIMATION"

Intensive care, or critical care as it is sometimes called, developed from the first artificial ventilation techniques employed during the polio epidemic in Denmark in the 1950s. Indeed, mechanical ventilation, and its history, parallels the development of the ICU (Puri et al., 2009: 195). After the development of increasingly sophisticated ventilators came heart monitoring and resuscitation technologies in the 1960s, followed, a decade or so later, by technologies designed to monitor other vital functions (Goméz Rubí, 2002: 25-27). Today, intensive care incorporates and centers on organ and system supplying technologies. The patients are acutely and severely ill or injured and as a rule, all suffer from life threatening conditions which are presumed to be reversible. ICU patients are often unconscious or in a state of reduced lucidity, where as much as 80% may lack capacity to consent to interventions (Ruston, Palmer, et al., 2009: 3).

The ICU is a special place in which the patient passes a particularly critical stage in their illness, then returns to life as it were, either through exiting the hospital all altogether or, more commonly, being transferred to a 'regular unit.' The French term for intensive care: *réanimation*, from the Latin *re* – again and *anima* – soul, translating literally to a return of soul or a return of life, is revealing of this most central feature. Indeed, there can be no doubt that intensive care and the organ sustaining treatments it offers have saved the lives of many patients. Yet its treatments are also inherently risky. When the body's functions are taken over by medical and technological means, they stop working by themselves. Moreover, prolonged intubation may lead to additional infections as well as weakened lung capacity, and prolonged immobilization can cause bedsores as well as muscle atrophy. The highly invasive, machine driven character of intensive care, together with the critical and severe conditions of its patients, lays the ground for many situations where intensive treatment is begun, but ultimately proves inefficient and the patient's life may not be saved.

WAYS OF DYING

Death in the ICU occurs in one of two ways. Some deaths occur suddenly irrespective of treatment initiatives. For instance, a patient may unexpectedly go into cardiac arrest with efforts to resuscitate proving unsuccessful. Indeed, in the case of critical patients, this may occur at any time, not least during routine activities such as cleaning or turning the patients' body, giving rise to what a Spanish physician somewhat jokingly called "las higienes matadoras" (the murderous hygienic routines). Efforts to resuscitate are substantial. For example, once in the Norwegian clinic, a patient had, in the words of his physician, "died eight times during the night", and he was awake and lucid the next morning. Moreover, in the French clinic I witnessed a cardio-vascular resuscitation of a severely sick patient that went on for a good 40 minutes.

The remaining 25-75% who die in intensive care, do so following a NTD on the part of the personnel, and (most often) in agreement with the next of kin. NTDs comprise a decision not to initiate treatment, as well as withholding or withdrawing treatment. To withhold treatment means to refrain from administering or initiating further treatment measures. For instance, a decision can be made not to initiate dialysis should a patient's kidneys malfunction, or a decision not to administer a new round of chemotherapy. When treatment is withdrawn however, this indicates an active removal of treatments that are already in effect. For instance, in keeping with the aforementioned example, this could mean shutting down dialysis, or even turning off the artificial ventilation (colloquially known as 'pulling the plug'). However, when we talk about withdrawing, withholding, or refraining from initiating treatment, we are referring *only* to life-prolonging or life-sustaining efforts. Palliative treatment is never forgone and in situations of withholding or withdrawing treatments, such measures may oftentimes be augmented (Materstved and Bosshard, 2009). NTDs never include abandoning so-called comfort care, such as pain relief or sedation. On the contrary, palliative care and symptom management is an integral part of working in the ICU (Klepstad, 2008).

FINDINGS

Making a non-treatment decision

In the English language, the basis upon which NTDs are made, are most commonly phrased as an evaluation of *medical futility*. Futility is a varied and contested concept however, and some authors wish to remove it all together. Engaging in a discussion on this topic exceeds the scope of this article. Nevertheless, the issue concerns recognizing at which point administering further life-supporting or curative treatments would no longer be in the patient's best interest, and thus carrying out an order of withholding or withdrawing further treatments.

Unsurprisingly, the stakes being what they are, and given the uncertain nature of medicine, there is disagreement on whether this is indeed a scientific, rational decision based on calculations of probability, or whether it is, at least in part a value-based decision (Wilkinson and Savulescu, 2011; Heland, 2006; Kasman, 2004). In the language of the law, withholding and withdrawing treatment are not considered to cause death, and the two are considered of equal value by most bioethicists. Nevertheless, research shows a somewhat greater resistance to withdrawing than to withholding treatments, as the former is perceived to involve more personal agency and more responsibility (Gedge, Giacomini and Cook, 2007: 215). Furthermore, this was the point where nurses often told me they did not envy the responsibility of the physicians. As one nurse said, “Luckily that's not my area, deciding that enough is enough.” When probing staff about this issue, I was surprised by their answers. In interviews and talks with ICU personnel, both nursing and medical staff in all three countries almost unanimously described death following a NTD and sudden death to be experienced as equal; moreover, they claimed that the latter was *harder* than when patients died after NTDs. As an experienced Spanish intensivist said: “A death that you consider explainable, in light of all the interventions that have been made, does not make you feel bad.”

Not having done enough

> Unfortunately, we do not always limit treatment. And I say unfortunately, because the patient where a non-treatment decision is not made is a patient who, in my opinion, should not die (intensive care physician, Spain).

There is a sense of disappointment or of potential professional failure associated with sudden deaths in the ICU. One intensive care physician told me that the level of intensity, urgency, and ultimately disappointment was much greater in patients for whom you had to fight "until the last moment." She commented,

> The patient who has a chance… because they are young, or healthy, or they've been in an accident… you have to try everything for this patient. Everything. You make a non-treatment decision when you say "we've done everything and he's not responding." In patients where there is no non-treatment decision you have to resuscitate if they go into (cardiac) arrest. If there's a complication, you have to treat it. You keep doing and doing, and despite all this you fail (intensive care physician, Spain).

Patients who die unexpectedly during the course of treatment defy the logic of rescue medicine according to which patients should not die (Chapple, 2010). Indeed, in these cases the team has not yet had a chance to *do everything*. There is therefore a feeling of not having done enough, of someone dying needlessly. Death is only acceptable when they have exhausted every medical and technologically available resource. Consider the following quotes by a nurse's aide and a nurse:

> Death following limitation (non-treatment decisions) is the easiest. Because you have time to grieve. In a non-treatment decision, there is a logical chain of events. You grieve in peace. The unexpected death overwhelms you. Indeed. In limitations you have tried it all. There is no other way out (nurse's aide, France).

> It's just a lot of effort that you've put into this person's survival, day after day, after day, with them and with their family. And then in the end they die! It's a personal failure (nurse, Spain).

On the one hand, this may be taken as evidence to support the concern voiced by Kaufman and Morgan (2005): "Death could become *a matter of deciding when a person should die and when a person should be considered dead*" (in Green, 2008: 61 emphasis in original). This makes physicians appear somewhat capricious. However, in my study, I never encountered expressed wishes to vanquish death. Nor were treatment or medicine posited as an opposition to nature. As a Norwegian intensivist said:

> We know it is part of reality. And it is supposed to be so, because, well, the patients are in very poor condition, and so we know that some will die. We have the possibility to prolong life with technical means. But that would be going against nature. When everything

> points in the wrong direction, we have a duty to assure a natural development of it. It is contained in the concept of dignity (intensive care physician, Norway).

More commonly, treatment was conceptualized as a practice of *buying time*. Indeed, it was often remarked that it was the body of the patient who would heal itself. The task of medical and nursing personnel was to provide it with a suitable environment in which to do so. Consider the following quote from a nurse when questioned about what it meant to treat the patient:

> One aspect is the material…. Using machines or medications … well, supporting the organic functions so that the patient can determine, or his systems or inherent power, or whatever you want to call it, may be regenerated through the time that we buy (for him) (nurse, Norway).

In this sense, in situations of sudden death, the team had failed not only in exhausting all options but they had failed to buy the patient enough time.

Death is not an acceptable outcome

Another aspect often pointed out in relation to the different dying trajectories most often witnessed in the ICU, was the relationship with next of kin. In theory, the next of kin need not agree with a decision to limit treatments. Yet it appears that physicians and nurses unanimously prefer this, and are prepared to wait to conduct multiple conversations with them, in order gain their agreement. There seemed to be a consensus that information should be given to the next of kin gradually, while maintaining the same level of treatment; they did not want to act against their wishes yet they also did not want to confront them with the whole situation at once. This observation is supported by Jox et al.'s study, according to which intensivists preferred an "indirect and stepwise disclosure of the prognosis" (2012: 543). Indeed, it was pointed out to me on several occasions that because patients who enter the ICU often do so after a sudden trauma, such as accidents, aneurisms, or sudden worsening of a pathological condition, they arrive unprepared. Therefore, death might in many cases be an unacceptable outcome to the next of kin, and this was a problem. As such, sudden death creates additional work, especially for nurses, because the next of kin – unprepared for this outcome - need care, answers, and support.

It is not only for the sake of the next of kin, however, that the sudden death proves challenging. Sudden deaths may also be experienced as a failure by staff.

A foreseen versus a sudden death

When a decision to withhold or to withdraw treatment has been reached, a time is set for the intervention to take place. Until then, treatment continues as before, making time for family members to arrive at the hospital.

> If the closest family lives in another city or something, they have to fly in. We try to consider these things …. And the framework around it all. That it happens calmly and with dignity. If they [next of kin] have any special requests, let's say they want some music, a priest, anything… or if they want to participate in washing [the deceased]. We care about those things (nurse, Norway).

In some cases, this involves waiting for a day or more. Efforts are made to render the patient's space private and undisturbed. Other measures are also undertaken which may be specific to each unit, such as lighting a candle in the hallway in the Norwegian unit, signifying that a death is taking place. Following a death in the French unit, a nurse's aide brought a tray of refreshments and some food for the family to be consumed inside the patient's room after death had been declared.

The next of kin may call upon a religious figure to be present, they may bring flowers and pictures, and in some places light candles inside the room. If the unit does not have single rooms for patients, curtains are drawn to ensure a measure of privacy. When treatment is withdrawn, all things considered *artificial* are removed from the patient's bed. The flow of medications and the attached machinery are not simply turned off, but are removed physically. Unnecessary apparatus is put aside, the exception being of course those that administer palliative measures. Indeed, the continued and possibly intensified palliative care is essential to procuring a dignified death in terms of alleviating pain and other symptoms, and in some cases sedating the patient. On the one hand, this ensures that the patient is not in pain or experiences unnecessary discomfort; however, it is also important to convey this to the next of kin and even to the attending nurse. Indeed, even in the case of a patient whose condition was near-brain death, and who had been kept on so-called life-support in the hopes of a possible organ donation but whose treatments were eventually turned off, was administered both morphine and sedatives. The doctor admitted to me that there was not *really* any chance that the patient could feel anything, but it was important that the nurse felt comfortable, so the doctor gave her the "freedom to give the patient whatever she sees fit."

Watching and interpreting the many monitors attached to each patient in intensive care is an integral part of working in the ICU. It is also a feature that captivates outsiders – myself included. "We often tend to focus on concrete parameters" a Norwegian nurse told me. "Blood pressure, pulse, antibiotics… Things that it is safe to talk about." Indeed, technology is not only captivating; the tangible and impersonal character of measurements and calculations is such that they seem unthreatening, safe topics in order to avoid the "real issues." When a patient is dying, there is a strange familiarity with these mechanic devices; for example, the famous "flat-line" as an indication of death, is something which most people are familiar with through watching TV and films. Intensive care personnel are aware of the absorbing lure of these features, and in expected deaths, the monitors may even be removed from the room, and physicians follow their output from a separate office. The intention, I am told, is to make sure that the next of kin do not get "caught up" in it or distracted by watching the screens, and rather focus on the patient. Indeed, despite the pervasiveness of technology in the ICU, most of the nurses with whom I interacted, said they preferred the relational aspects of their jobs. Furthermore, there was no necessary contradiction between this on the one hand, and expressing compassion and so-called soft skills on the other, and the more experienced a professional is, the less they rely "blindly" on technology (Almerud et al., 2007; Alasad, 2002). Thus, technological competence and familiarity in fact favors non-technological caregiving.

When death occurs suddenly, the next of kin might not be present. If they are, the scene is likely to be one of an emergency. The aesthetic qualities of a resuscitation scene are quite unpredictable. Indeed, whereas nursing staff in particular pay great attention to assuring the patient's bodily integrity through covering them, containing liquids, closing doors or curtains, speaking softly and minding their touch; situations of emergency do not allow for such concerns. Nudity, bodily fluids, loud voices, and "action" are commonplace – scenes that may indeed prove stressful and undignified to next of kin. Moreover, there is no guarantee that they would be allowed to be present, as space in a patient's room or area is limited; many professionals prefer to make the next of kin leave when procedures are undertaken.

The makings of an acceptable death

> "Whatever background you have, I think most people wonder a bit about it. Even though I have participated in ending the treatment of many persons and I have watched them die here, there is still some degree of wonder attached to it. It's sacral almost. I find it meaningful to handle such situations: helping the family and the patient get through it in an okay way" (intensive care physician, Norway).

In contemporary Western ideals of natural death (which is equated with good death), Jane Seymour argues that it is not the cause of death which is at stake. It is the way in which death is *handled*, and the circumstances surrounding it. It is the process of dying as opposed to the moment of death itself, which is the key determinant of the manner in which death is viewed (1999: 692). Del Veccio et al., (2004) have developed three main areas by which physicians evaluate deaths in which they have been involved: time and process, medical care and treatment decisions, communication and negotiations. In a study conducted by the authors, futile and overly aggressive care were associated with bad deaths. Positive features included that death be "expected," "peaceful," and "timely" and including "effective communication with patient, family, team" (2004: 944, Fig. 1). Furthermore, as Seale writes in his article on the cultural representation of dying alone (2004), there are powerful contemporary accounts of death and dying that emphasize a confessional and heroic dying subject, surrounded by a loving family and/or friends, together with good medical and nursing care. "Such deaths," he writes, are depicted as profoundly sociable affairs" (2004: 973). Furthermore, La Marne adds that common ideas of a good, dignified death include a certain level of hygiene (2005: 92). On the one hand, this is a pragmatic concern, regarding bodily fluids. On the other hand, it is an aesthetic concern, where a dignified death in our contemporary imagination often includes having ones affairs in order, a level of heroism or at the very least a profound mental and (slightly less so) physical autonomy until the end, as well as having achieved some acceptance beforehand and thus "going quietly."

Furthermore, Timmermans concludes that death would oftentimes prove (more) senseless to our modern Western sensibilities were we *not* to attempt resuscitation (1998: 162 my emphasis). In this sense, having attempted to save the patient's life provides the next of kin with more comfort. Rebecca Dresser (2004) points to the same issue arguing that for many patients and their families, it would indeed be the lack of aggressive measures or of "doing everything" to save a patient's life, which would prove the most harmful to their sense of human dignity (2004: 201).

What we have seen, is that if the ethical and procedural aspects of NTDs have drawn such wide interest, then, it does not necessarily reflect the feelings of health care professionals on the ground. When Moller claimed that "Technological death facilitates the loss of the dignity of the individual" and created "depersonalization, psychological mutilation and scars for unprepared family members" (in Timmermans, 1998: 147), this rings true only in a limited sense. Surely, deaths in the ICU can be seen as technological. Moreover, they often occur when the patient is in fact unconscious and therefore has little to no "self-possession." Yet it appears that it is here that intensive care personnel may, through medically timed deaths occurring after NTDs, be given the opportunity to fashion culturally acceptable, even good, deaths.

One the one hand, dying in the ICU very often involves a loss of conscious self-possession and conscious integrity, as partial or complete unconsciousness and sedation are integral parts of treatment in the ICU. Nevertheless, the idea of depersonalization as a result of this has been problematized by several authors (Bird-David, 1999; Kaufman, 2000; Bird-David and Israeli, 2010). Furthermore, great emphasis is put on making death acceptable for the next of kin, which oftentimes involves prolonged treatment, or treatment administered at more intensive levels than physicians would otherwise have wanted. Furthermore, there is no binary opposition between technology and "goodness" or human values, in intensive care. Indeed, for several of my informants, the most important aspect of their jobs was the relational; the human connection. Lastly and most importantly indeed, technologies are clearly a central part of achieving a good death (see also Seymour, 1999, 2000).

The practice of bringing pictures, drawings, or other tokens of affection at any time during a patient's hospitalization and especially in death, testifies to an effort of individuating and accentuating the social personhood of the patient. It follows from this however, that whenever there are no onlookers or family present, ritual is minimal. This may lend credibility to Ariès' critical observation that the desire for death to be acceptable was not least a feature emphasized for *those who survive it* (1975: 63). It remains uncertain however if this can be attributed to factors specifically related to intensive care. On the contrary, this must be seen as a result of a much larger social setting, such as a dissolution of family and community ties.

CONCLUSION

Understanding why physicians and nurses working in intensive care may feel more comfortable with deaths following NTDs as opposed to sudden death, requires an awareness of how death in the ICU fits with cultural conceptions of good and bad dying. My study shows no evidence to the effect that physicians or nurses wish to vanquish death, or exert control over nature. There is a sense of professional disappointment involved in sudden death, only to be expected from professionals trained to "save lives." An attitude emerges according to which one can indeed only know whether a death was unavoidable or not once all measures have been exhausted. When they have, and further measures appear non-beneficent, death becomes acceptable, and may be rendered *good*. Indeed, the ways in which foreseen deaths are carried out include important ritual aspects. Ideally, the next of kin have understood and agreed with the decision, and have been given ample opportunity to have their questions answered and to accept the death. The scene involves creating a certain aesthetic: the room is clean and uncluttered, the dying patient is calm and free from suffering. Freedom is given to the next of kin to be present at their loved one's deathbed, to bring tokens of affection, and say their goodbyes without technological or medical interruption. Sudden death does not confront medical personnel with the same ethical and procedural responsibility as does NTDs. Nevertheless, their perceived responsibility seems to be no less important. Moreover, sudden death offers none of the ritual and consolatory possibilities as deaths following NTD, and as such, stands out as a worse outcome.

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