

# EACME Newsletter

European Association of Centres of Medical Ethics

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Number 49 – August 2018

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## EDITORIAL

Summer is in full swing, dress codes have relaxed and the feeling within my own faculty has subtly changed: some offices are abuzz with interns who bring fresh energies and insights to their summer placements. Other offices quietly hibernate as the usual occupants are absent on holidays. Still others are infused with the almost palpable studiousness of academics at last finding time to complete a paper on a treasured topic, or flesh out plans for the next academic year. So, everything is changed. But in other ways nothing is changed. The Nuffield Council on Bioethics has published a report arguing for the ethical permissibility of the modification of DNA in human embryos.<sup>1</sup> The report contained careful treatment of the issues, leading to a conclusion that genetic modification must both be in the best interests of patients and in no way create or exacerbate inequalities. Despite this, there have been regrettable, if predictable, misinterpretations in some sections of the news media, with some outlets reporting that the report endorsed creating 'designer babies' engineered for looks and intelligence. Regular readers of the newsletter will notice a familiar theme here: when even the most nuanced ethical debate is so wilfully misinterpreted, it is deeply demoralising. Of course, we must not retreat to our silos, but it nevertheless makes places where debate is more intellectually honest and genuinely inquisitive a welcome respite: I hope you find EACME such a place, and, for this reason among others, I am looking forward to our conference later this year (of which, I shall leave the Ruth Horn's report from the Bureau to give more details).

<sup>1</sup> Nuffield Council on Bioethics (2018) Genome editing and human reproduction: social and ethical issues  
Available at: <http://nuffieldbioethics.org/wp-content/uploads/Genome-editing-and-human-reproduction-FINAL-website.pdf>

If (avoidance of) misinterpretation is one familiar theme, this newsletter continues others. Among the articles are two highly personal pieces that reflect on the history of EACME: Richard Nicholson continues the work started by Paul Schotsmans in the previous newsletter of providing his own recollection of the beginnings of EACME which I think adds to prior work of this nature significantly. My colleagues Mari-Rose Kennedy and Richard Huxtable document more recent EACME history, with a lively account of the special valedictory seminar for Ruud ter Meulen, our previous EACME president. Meanwhile we carry reports of both the 14th annual International Conference on Clinical Ethics and Consultation and the special conference for the 20th anniversary of the Oviedo Convention on Human Rights and Biomedicine. I heartily thank our contributors for these pieces, as well as our other reviews and reports. I think you will find them interesting and enlightening reading.

Giles Birchley, editor

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## NEWS FROM THE EACME BUREAU

Dear colleagues and friends,

We hope this Newsletter finds you well. On behalf of the Bureau, I would like to share some of the latest news with you.

On June 20<sup>th</sup> Rouven, Bert, Angelique and I met for our annual Bureau meeting in Oxford. Among other things, we discussed the membership applications from three new (old) centres and are very pleased to welcome 1) Prof. Dr. Silviya Aleksandrova-Yankulovska from the Bulgarian Association of Bioethics and Clinical Ethics (BABCE) who joined us as an associate member; 2) Prof. Dr. Yesim Isil Ulman from the Bioethics Department of the Acibadem University, Istanbul (Turkey) who joined us again as an associate member and; 3) Prof. Dr. med. Jan Schildmann, M.A. from the Institut für Geschichte und Ethik der Medizin, Martin-Luther-Universität Halle-Wittenberg (Germany) who joined us as a full member.

It is wonderful to see the EACME growing and attracting both, well established and young members in the field of bioethics. This year's conference in Amsterdam will provide an opportunity to meet our members (and non members) in an 'informal, welcoming, multidisciplinary and interactive' environment (see April Newsletter). The latest update from the conference team at the VU University Medical Center (VUmc) is very positive and promises an exciting EACME 2018 conference featuring 'Ethics in Action' ([www.eacme2018.amsterdam](http://www.eacme2018.amsterdam)).

Our Bureau meeting also gave the opportunity to discuss next year's conference that will take place on 12<sup>th</sup>-14<sup>th</sup> September 2019, in Oxford. Our organising team at Ethox presented the conference theme 'Rethinking Ethics in 21<sup>st</sup> Century Europe' and discussed sub-themes and key-note speakers with the Bureau. We also visited the conference venue, the Keble College which was founded in 1870 and is one of the largest of the constituent colleges of the University of Oxford. The College has a continuing commitment to inclusiveness. We will provide you with more details about our EACME 2019 Oxford conference in Amsterdam!

In the meantime, I wish you a good summer and look forward to seeing you in September,

Ruth, on behalf of the Bureau (Rouven, Bert and Angelique)

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## FAREWELL TO A PROFESSOR (AND PRESIDENT)

On 16 November 2017, the University of Bristol's Centre for Ethics in Medicine (CEM) had the pleasure of hosting a special valedictory seminar for Professor Ruud ter Meulen. Many students, colleagues, friends and family were in attendance, including Ruud's wife, Hettie, and Professor Gordon Stirrat, the founder of CEM. This special seminar allowed CEM to bid farewell to Ruud and also celebrate his latest book, [\*Solidarity and Justice in Health and Social Care\*](#) (CUP, August 2017).

### *Solidarity and Justice in Health and Social Care*

Ruud was originally a psychologist, but he has worked in the field of bioethics for most of his career. He was based in Maastricht University in the Netherlands, before moving to the UK in 2005, where he took on the role of Director at CEM in Bristol, staying for 10 years before retiring in 2015. During his career, Ruud has worked on a wide range of bioethical issues, in addition to solidarity and justice, including research ethics and integrity, human enhancement and synthetic biology, care of older people, and assisted dying and euthanasia. Ruud also collaborated on numerous European research projects (such as [PRINTEGER](#) and [EPOCH](#)), as well as working with various professional organisations, such as the UK's Nuffield Council of Bioethics on their [report on dementia](#). He also, of course, is well known to EACME, having long participated in its work and recently been President.

The seminar began with Ruud presenting an overview of his work on solidarity, including his recent book *Ruud*

became particularly interested in the concept in the early 1990's and he began to notice problems with the concept and the growing popularity of the alternative concept of justice. However, more recently, the bioethics community has showed a renewed interest in solidarity, exemplified by its inclusion in the Nuffield Council on Bioethics report on dementia, after which, in 2011, the Council commissioned a short study exploring solidarity.

Ruud brings his thinking about both solidarity and justice together in his 2017 book. The book involves a multidisciplinary analysis of the concept of solidarity to explore its potential to contribute to bioethics. This includes engagement with the sociological origins of the concept and a philosophical comparison of solidarity and justice. Ruud also analyses the role of solidarity in social care policies, focussing on family care and vulnerable individuals. The book explores how the idea of solidarity can be associated with mutual respect and support and commitment to a common cause, such as in collective systems, where the better-off help those less fortunate, and everyone is assumed to make a fair contribution to society. This has meant, however, that solidarity has been criticised for being a communitarian concept, which fails to account for individuality and individual preferences and appears less compatible with non-European societies, such as the USA.

Such perceived problems have prompted some to argue that justice is the better concept for analysing burdens and benefits in healthcare and their distribution, in ways which better account for individual rights. But Ruud argues that solidarity still has a place in health and social care because it promotes a relational approach to bioethics, which can complement justice, advocating 'reflective solidarity' that can account for individual differences. Moreover, he argues that governments and health systems need to support families and individuals to practice solidarity and that solidarity can and does exist in non-European communities.

### ***Exploring Bioethics and the Blues...***

This special seminar ended with questions – both from the floor and from other sources – that were chaired by Richard Huxtable, Ruud's successor as director of the CEM. The questions and answers engaged with Ruud's work on solidarity, as well as his other work in bioethics. But, fittingly, the conversation also invited more personal reflections – including, as those who know Ruud might expect, some talk of the blues...

Regarding Ruud's recent work, former CEM colleague Professor Muireann Quigley (University of Birmingham) tweeted for clarification of the utility of solidarity, while Professor Stirrat asked Ruud to expand on the relationship between solidarity, justice and relational autonomy. Ruud explained how Habermas argues that

solidarity and justice are two sides of the same coin and are indeed compatible. For example, solidarity can involve a rational calculation, such as payment of social insurance for healthcare, as well as accommodating more emotional understandings. Dr Jonathan Ives, also from CEM, further probed the complementarity of solidarity and relational autonomy, with Ruud replying that relational autonomy is a way of seeing autonomy as flourishing in a state of solidarity with others. Another CEM colleague (also since sadly departed), Dr Anna Pacholczyk (St George's University), commented that solidarity has similarities to empathy, providing an underpinning of why we care about others, to which Ruud agreed.

Turning to Ruud's career in bioethics, a former PhD student of Ruud's, Dr Alex McKeown (University of Oxford) tweeted his question. He had spent three years trying to decipher Ruud's views on human enhancement and asked: "Once and for all, all things considered, is Ruud in favour of enhancement or not?" To the amusement of the audience, Ruud replied that this was a tough question and that he is not in favour of enhancement, but not against it... The mirth was amplified, when it was revealed that Alex had predicted this in his tweet, writing "I bet he says 'it depends'". Jonathan Ives mischievously enquired "where do you sit on fence sitting?", a question that understandably went unanswered!

Another of Alex McKeown's former PhD advisors, Professor Helen Lambert, highlighted how she felt it was important that Ruud had encouraged his PhD students in bioethics to engage with empirical work, as well as philosophical analysis. This initiated a discussion about the value of empirical bioethics research. Jonathan Ives noted the power of emotive narratives and Ruud observed that people can be attracted to positions that fit with their worldviews, which suggested to him a need for a deliberative approach and for achieving understandings, without holding that "one-size-fits-all" in bioethics.

Richard Huxtable extended this line of enquiry, asking whether there is such a thing as "European" (or Dutch, British, and so on) bioethics? Ruud suspected there was a different emphasis in different cultures, influenced by such factors as history and religion, which can lead to different weightings or emphases on certain values. This discussion led on to an exploration of law's potential influence on solidarity. Ruud noted that the concept of solidarity had some historical grounding in Roman law, where families were responsible for the financial obligations of their members. Furthermore, sociological discussions about the concept have highlighted that, for solidarity, individuals need to suppress their own interests and desires and governments arguably have an important role in

restricting individuals to facilitate solidarity, but this can lead to tensions between individuals and the government, especially in individualised societies. Ruud concluded that, whilst governments can support certain practices, it is difficult to use law to promote solidarity amongst individuals, as they have to accept those values – and the government.

The session ended with a quick-fire round of questions, starting with “How retired are you?” The predictable academic answer followed: “Semi...” Dr Peter Novitzky (University of Twente) tweeted to enquire about Ruud’s reading and writing plans post-retirement, to which Ruud answered that he was thinking about justice and enhancement and was visiting the Brocher Foundation in Geneva in 2018 to work more on this (Alex might yet get his answer!). Angelique Heijnen, a longstanding colleague of Ruud’s from the Netherlands and from his work with EACME, also tweeted to ask: “Looking back over your career, what are you most proud of?” She also asked a less serious, but no-less pressing question: “is Ruud considering continuing his famous St Nicholas career now that he is back in the Netherlands?” (Ruud is known amongst the Dutch community living in Bristol because each year at Christmas he has dressed-up as St Nicholas, embodying the great giver of presents, the purveyor of Christmas cheer). Ruud explained that he had certainly retired as St Nicholas, not least because the big beard that the costume requires is so awful and uncomfortable! As to Angelique’s first question, Ruud explained that he was proud of completing his book on solidarity as that had been a long-term goal, was proud of his enjoyable work in various European projects, and was particularly proud of the people that he’s worked with who have created the community at the CEM in Bristol.

The final question, courtesy of Professor Mike Parker (University of Oxford), brought to light one of Ruud’s lesser known talents, as a blues- and jazz-influenced, honky-tonk pianist. Mike asked, “what is Ruud’s favourite jazz piano solo and why?”, and offered bonus points if Ruud could link his answer back to bioethics. Ruud had an answer, which neatly brought together the various themes of the seminar: “The music that I play in solidarity with the black community, people of colour in America.”

The seminar confirmed that Ruud is a talented, well-respected and popular man. Those who could not attend – such as former colleagues Anne Walsh (Bristol) and Dr Ruth Horn (University of Oxford) sent virtual love, thanks and hugs, which prompted a real hug from the Chair. The staff and students at the CEM will miss Ruud greatly and wish him all the very best in his (semi?) retirement.

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## THE HISTORY OF EACME: ANOTHER PERSONAL REFLECTION

*Editors note: Following on from Paul Schotsmans article on the early years of EACME in the April 2018 newsletter, I am pleased to present a second article on this topic from Richard Nicholson.*

The original idea for EACME came from Francesc Abel of Barcelona, Maurice de Wachter of Maastricht, and Jean Francois Malherbe of Brussels, but history does not relate which of them could claim priority. They invited representatives of other European centres to Brussels in May 1985 to explore whether such centres could usefully collaborate. There were seven centres at the meeting – Lyon, Lille and Centre Sevres (Paris) from France, London and Oxford from the UK, Brussels (Belgium) and Maastricht in the Netherlands.

It quickly became clear that there were many ways in which centres could cooperate even before the wonders of the internet. The aims of the new association were agreed to be:

1. To provide institutional members with information about ethical problems in health care
2. To provide research tools such as documentation, access to data banks and regular information
3. To coordinate collaborative research and to exchange research results more generally
4. To contribute to European debates on bioethics, and
5. To promote the teaching and study of ethics among those involved in health care.

It was during the 1980s that public and governmental interest in medical ethics took off. Assisted reproduction technologies were being developed, organ transplantation was expanding, the persistent vegetative state was recognised as causing ethical problems, public opinion in many countries was supportive of legalising voluntary euthanasia, and examples of unethical medical research became more frequent. So, there was value in emphasising information exchange in the new association, because many of the institutional members found themselves advising their own governments, and the EU and the Council of Europe.

As well as the aims listed above, there was also a, generally unspoken, purpose of wanting to ensure that European medical ethics was not dominated by American bioethics. The late Benjamin Friedman of Montreal told me that the great flowering of bioethics from 1970 was the result of 95% unemployment among post-doctoral philosophers in North America in the late 1960s. Those brought up academically in Europe knew, however, that there was a much richer philosophical background than was shown in bioethics. By the mid-1980s, Beauchamp and Childress' "Georgetown mantra" – of respecting the principles of autonomy, justice, beneficence and non-maleficence – was already becoming popular. After all, the clinician could just recite the mantra - autonomy, justice, beneficence and non-maleficence - at the bedside, and any ethical dilemmas would be solved. The danger of American domination was made clear in 1986 when a group of American bioethicists started fundraising for a "European Bioethics Center", apparently unaware that there were by then at least 20 centres of medical ethics in Europe. Some Americans still remind me that at the time I called this 'American bioethical imperialism'.

The original group met again later in 1985 to start hammering out a constitution. There was quite a dividing line between the British and Dutch, who wanted a simple, pragmatic document, and the French and Belgians who wanted a much more baroque structure under French law. The divide more or less matched the language question between English and French that Paul Schotsmans mentioned in his history in the last newsletter. The need to work in both French and English was a problem for most Anglophones – I had been to school in Germany and was reasonably bilingual, but in the wrong language. The move to working in only English must be causing similar problems for our Francophone members.

#### *Early meetings*

I thoroughly enjoyed those first two meetings. Among the seven centre leaders, plus Francesc Abel, three were doctors and one a scientist. As a doctor, it was curiously affirming to be in their company. My interest in ethics had started as a medical student in Oxford, protesting to the professor of pharmacology about the number of animals slaughtered on our course. He told me to write him a paper. I did so, concluding that the use of animals was needlessly excessive, very expensive, a poor learning experience, and illegal under the 1876 Cruelty to Animals Act. I failed pharmacology. The professor took my resit viva, unusually by himself, and spent the 20 minutes telling me why medical students know nothing about running medical courses. Rather than take his advice to stop

worrying about ethics, I went the other way. By 1985, having run a working party on the ethics of medical research with children, I was the only doctor in the UK working full-time in medical ethics. So it was good, in Brussels, to feel less alone.

It was good, too, to start meeting some of the fascinating non-medics who then inhabited medical ethics, like Patrick Verspieren, the ordained director of the Centre Sevres. A story is told of him walking home in Paris with a colleague and being pestered by a 'fille des rues'. She kept addressing Patrick as 'mon petit lapin' and would not leave him alone. Finally he opened his overcoat enough to reveal the dog collar underneath. 'Dommage' he said 'j'ai myxomatose'.

There were good and able people at the early meetings, and perhaps the lengthy care they took over accepting new members – even of the calibre of Paul Schotsmans and his centre – reflected a need for it to be an irreproachable organisation from the start. Incidentally, in his article in the last Newsletter, Paul did himself out of a year's history. The Lyon meeting, at which the candidatures of Leuven and Rome were lengthily reviewed, took place in January 1986. So, the Leuven centre must have started in 1985 (unless Paul applied for a yet-to-be-created centre and took us all in!). My only memory of the Lyon meeting is of the contrast between the bleak and functional, white-tiled room in the forensic medicine institute where we met, and having dinner at one of the great restaurants for which Lyon is famous.

By the second meeting of 1986, held at Maastricht in the autumn, membership of EACME had risen to 16. The articles of association were adopted, and it was agreed that the first collaborative project should be to establish a computerised bibliography of European books and papers on medical ethics.

The first meeting of 1987 was held in London and exchanged information about the wide variety of ways in which ethics review of proposed research was conducted. National systems ranged from the non-existent, even in a major country like Italy, through the well-organised but fairly new arrangements in Denmark, to the older but quite disorganised system in the UK. I think the meeting achieved its purpose, but I did make a serious mistake in arranging it. I assumed that most ethicists were not particularly well paid, and booked members into a tourist hotel near the meeting venue. It was made clear to me that members expected a much higher class of hotel, even in central London where such hotels charge exorbitant rates.

For me, the next meeting was probably the most memorable, because there could be no question about the standard of accommodation, and the surroundings

were stunningly beautiful. The Hastings Center is probably the most collaborative North American centre. It persuaded the Rockefeller Foundation to host a meeting of North American and European centres at its European study centre – the Villa Serbelloni, which sits in marvellous gardens above the village of Bellagio on the shore of Lake Como. Even in February it was all too easy to let one's gaze stray out of the meeting rooms' windows to the beauty outside.

The subject of the week-long meeting was informed consent, but its main purpose was to explore possible transatlantic collaborations. An extraordinary range of attitudes to informed consent was revealed. On entering most Italian hospitals, patients had to sign a document agreeing to any treatments the doctors might recommend. In Spain, a similar form of (generally) benevolent paternalism was still the rule, but increasingly challenged. Surprisingly, in Leuven doctors were trying to go a step further: they wanted it to be accepted that anyone who came to the university hospital thereby gave implied consent to being used as a research subject. In Canada and the US, on the other hand, informed consent was a well-defined legal concept to which every patient had a right. The Bellagio meeting led to several collaborations in education and multi-centred research, as well as exchanges of visiting scholars.

My presence in EACME was as a representative of the Institute of Medical Ethics in London. Unfortunately it hit really serious financial trouble in 1989 and closed down nearly all its activities. The Bulletin that I edited was cut loose and I had a struggle for several years, not only to keep it going, but to get it to the point where it provided some sort of a living. For any budding young medical ethicist who wants to be independent of institutional pressures, the answer is to have a spouse with a steady job he or she enjoys.

I therefore missed some EACME meetings, coming back to the association at Pecs in Hungary in 1994 as an associate member. Our charming host, Bela Blasszauer, was careful to look after his guests' bodies as well as their souls. A coach met many of us at Budapest airport to drive us south down the Danube valley to Pecs. At sunset, we stopped for dinner at a restaurant on a bluff overlooking the river. Many of us were persuaded to have *szegedi halaszle*, a local specialty soup that seemed to be half fish and half paprika; one needed to drink twice as much beer as soup to stop one's throat burning. One afternoon we were taken further south, close to the Serbian border, for a wine tasting at a vineyard; the owner was glad we had chosen a quiet day – most days one heard the thunder of artillery being fired just over the border in yet another Balkan war.

### *Does EACME miss the big issues?*

EACME had changed while I was away. It had grown, and it had developed better administration. Part at least of its meetings was open to anyone interested. But it had also made, in my view, a serious mistake. To encourage individual centres to take on the organisation of annual meetings, it ceded to them the right to choose the subjects of the meetings. The result was a sort of sameness from year to year. Sometimes it is obvious as when the 2011 meeting on cross-cultural bioethics followed a meeting on bioethics and multiculturalism two years earlier. What we have not been providing are meetings that are keeping up with the big issues in medicine and public discourse.

Take for example the five subjects mentioned in the third paragraph of this reflection. Assisted reproductive technologies have remained a matter of public interest and discourse throughout the life of EACME: we have never had a meeting concentrating on them. Likewise, we never had a meeting on transplantation, although there was one on the persistent vegetative state in 1996. Voluntary euthanasia and surrounding issues have been parts of various meetings, with one in 2002 devoted to end-of-life decisions. Research ethics was last the subject of a meeting in 1989, yet there has been massive debate on the subject since 1998. It was then that the American pharmaceutical industry started a very unpublic campaign to have the rules and regulations relaxed so that their research would be quicker and cheaper – and less ethical. Fortunately, it became public knowledge.

There are other subjects full of medical ethical dilemmas that have never appeared on meeting programmes. How is it that in the 1990s AIDS was never considered important enough for its own meeting? Military medical ethics can be a fascinating area, with large parts of the Geneva Conventions being about medical ethics in wartime. Yet the protections for health care workers in war are under real threat because they have been ignored for years by the totalitarian regime in Syria, led by a doctor (Assad was an ophthalmologist in a previous existence). No one is yet asking how to strengthen the Geneva Conventions, but medical ethicists could take a lead.

Those of you who have listened at all to me in recent years will know what is coming next: the extraordinary absence of climate change from EACME programmes. Given that the fundamental problem is too many human beings using too many natural resources too fast, and that the only workable solutions will require drastic changes to western lifestyles, there are numerous issues that could interest medical ethicists:

- 10% of global GDP is spent on healthcare for one-seventh of the population; how do we ensure equitable provision of healthcare worldwide?
- How do we reduce the population without resorting to murder?
- Do we withdraw curative care from the over 70s and just provide palliative care? Or from younger people as well?
- Can we outlaw all forms of assisted reproduction?
- Should we allow epidemics and pandemics to happen? They are nature's way of keeping us in check – perhaps nature should take its course?
- Given that social factors – clean water, clean air, good housing, refrigeration – are the main determinants of longevity, do we need any medical care?

Setting up EACME in 1985 allowed its members to have some influence in European discussions and the making of laws and regulations. That could happen again, but EACME needs to look outwards, and so do individual centres.

In Europe medical ethics seems to have become all too often part of philosophy, with centres separate from hospitals and medical schools. When he was president of EACME in 2000, Paul Schotsmans wrote about training medical students in medical ethics: "Students need to learn the facts and concepts; they also need training in moral reasoning." Perhaps some centres need to look up regularly from the pressures of academic output requirements, to find out the facts about what is happening in healthcare and related areas, and to recognise new and important areas where their abilities in moral reasoning are needed. Then the faint sense of ennui I detect would be dispersed.

Richard Nicholson  
Founding father

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## UNDERSTANDINGS OF AUTONOMY IN ETHICS, LAW AND REGULATION

### Informed Consent: Understanding Autonomy

#### Background

Informed consent is an area where medical ethics, medical law and medical professional regulation intersect. Law and regulation set standards of disclosure aimed at securing respect for the ethical principle of autonomy. My PhD asks: Is there a coherent understanding of informed consent to surgery across medical ethics, medical law and medical

professional regulation? This article focuses upon the aspect of my research addressing the extent to which ethics, law and regulation have a coherent understanding of autonomy. The understandings of autonomy discussed are drawn from the ethical literature, and legal cases and General Medical Council guidance setting the legal and regulatory standards of disclosure.

#### Ethical Understandings of Autonomy

My research considers four key concepts of autonomy:

- (1) Kantian autonomy: People should reflect upon their reasons for acting and only act in accordance with principles all could follow.
- (2) Dworkin: People must reflect upon their reasons for acting to ensure they accord with their second-order desires, that is, desires they want to have.
- (3) Beauchamp and Childress: People must understand the nature and consequences of their action but do not have to reflect upon the reasons for it. Decisions to act should accord with their individual values.
- (4) Meyers: Decisions should be shaped by individual values, but those values are shaped by the world around us. Reflection upon the reasons for acting is not necessary.

#### Legal and Regulatory Understandings of Autonomy

Law and regulation share a similar understanding of autonomy.

- (1) Patients have the right of self-determination.
- (2) Information disclosure enables that right to be exercised meaningfully.
- (3) In deciding what information to disclose, doctors must take account of patients' values.
- (4) Patients must understand the information so they can reach a balanced decision if they wish to do so.

#### Coherence of Understandings

Whilst law and regulation have a coherent understanding of autonomy, the extent to which ethics shares that understanding depends upon the ethical concept of autonomy employed, particularly in the context of individual values and reasoned decision-making.

Individual values feature in law and regulation but do not feature in the Kantian concept of autonomy as he said we should act according to principles applicable to all. The other ethical concepts do feature individual values but take different approaches to the role they should play. Dworkin focused upon individual values you *want* to hold whilst Beauchamp and Childress focused upon individual values you *do* hold.

Ethical concepts of autonomy diverge as to the role of reason in decision-making. For Kant and Dworkin, reason is necessary for autonomous decision-making. In contrast, Beauchamp and Childress concluded understanding is sufficient. Law and regulation adopt a middle ground: understanding alone is not sufficient because information disclosure should *enable* reasoned decision-making, but the decision does not *have* to be reasoned to be autonomous. This reflects Meyers' concept of autonomy.

### Conclusion

There is a strong coherence between the legal and regulatory understandings of autonomy but the extent to which there is coherence with ethics depends upon the ethical concept employed.

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## INTERNATIONAL VISITING FELLOWSHIP IN MEDICAL ETHICS IN BOCHUM – GERMANY

### Deepening and Diversifying the Understanding of Advance Directives – International Visiting Fellowship in Medical Ethics. A personal view

June-July 2018, Bochum, Germany

*„States of mind, this is what should be taught to others; not contents, not advice, not precepts”*

C. Noica, Jurnal Filozofic (1944), Romanian philosopher

The Institute for Medical Ethics and History of Medicine, within Ruhr-Universität Bochum, Germany offer, every year, for doctoral or post-doctoral researchers worldwide, a scholarship and the possibility to spend up to three months in the Institute. The objective of the Institute's leadership is to promote international presence in Ruhr University and to strengthen the collaboration with other centers, institutes or universities. In this university year (2017-2018) I was one of the two foreign researchers involved in the program.

I decided to send my application for the fellowship for two reasons: first, I was interested to deepen the context of advance directive and to figure out how it could work in Romanian medical practice, and second to improve my experience of teaching medical ethics in a medical university, in terms of new topics, methods, and evaluation.

### Deepen the Understanding of Advance Directives in Romania

Lately, both Romanian medical doctors on one hand and patients with their families on the other hand, deal with situations where informed consent to medical procedures is not done in a proper way, because patients are not able to express their will anymore. Romania is one of few European countries that has no special law on advance directives yet. Romania ratified international legal frameworks as the Convention on Human Rights and Biomedicine (1997), and the last version of the Medical Deontology Code (2017) states that patient wishes, decided in advance, will be taken into account if he/she is not able to express them (article 16).

Analyzing complaints of patients or legal representative of patients in the last years within the College of Physicians and the debates on this topic, we can affirm that health care professionals consider that a special regulation for advance care directives in Romania would be beneficial, in order to avoid confusions and misunderstandings in the practice. But, these new concepts and documents also bring new issues and questions. Because of the health system in Romania, and the culture and customs, we are faced with technical and cultural problems related to advance directives.

**Technical Problems.** Advance directives on refusing specific treatments, usually, are not yet used in the Romanian medical practice. Why not? Because as they are not legally regulated, patients do not know how to draft them, and medical doctors do not know how they work. The only one exception known is in the case of Jehovah testimonies on refusing blood transfusion. Concepts like written informed consent, patients' rights, medical malpractice and liability have been known only for several years (2006, the adoption of the Law no. 95 on Health Reform). In the other hand, people are not educated in the culture of knowledge of rights, legal regulations, or medical ethics. In the case of patients who are not able to decide for themselves, the legal representatives are asked to consent or to refuse treatments, or the physician propose a treatment the family agree with. Implementing this document in medical practice is perceived as a change in daily activities.

**Cultural Problems.** Cultural problems concern the ambiguity in language, understanding of new concepts, interpretations, and difficulties in locating the advance care directives in the Romanian civil law system. In the Romanian Civil Code, the will ("testament", in Romanian) means a legal unilaterally act, personal and solemn, essentially revocable during the lifetime of the testator, by which a person has

ordered his fortune in whole or in part for the time when he or she will be died (Article 1034). Anyway, the meaning of the will is only dealing with patrimonial disposal and only after death. Another issue regards the lack of publications, monographic studies on the subject, and public debates. These topics have started to be present only in the academic fields, in the curricula of students or residents in the medical field. It is not a public debate on patient's rights, end of life decisions, or informed consent issues.

**Calls for a legal framework on Advance Directives in Romania.** By drawing up and implementation of these documents in Romanian medical practice, professionals won't be responsible for the consequences of the decision to stop treatments or to not starting some medical procedures. They can provide legal proofs of they do, in case of complaints in courts. They do respect decisions and choices of their patients, previously expressed. Advance directives could also minimize potential conflicts and misunderstandings between health professionals and relatives and avoid the fear of media scandals.

#### Which were my other activities?

During the program I was participated to *Research Colloquium*, I was joined the *Lunch Seminar Series*, and other meetings in the Institute. Also, I was invited to join courses on medical ethics, where I followed the course and I observed the reaction of medical students to ethics topics. Professor Jochen Vollmann taught topics related to *Research on Human Subjects* and *Ethics Committees*. The course was taught using interactive methods, students participated to the debate, answering to questions, providing their own interpretations and comments. The fellowship program in Bochum closed with me and my colleague's participation to the annual reception given by the Rectorate of Ruhr University for foreign researchers in Bochum University.

**What I learned?** – Good examples of the organization of the Institute activities, the leading of the team, discipline and transparency, the way of „sharing” ideas, news, projects and collaborations, reports about visits, food and friendship.

**What I took as a good practice to teach?** – To give space to students, to put questions and to listen their answers, interpretations, comments. To give feedback to students interactions.

**What I most appreciated?** – The organization of the Institute activities, the way of leading of the team, the atmosphere of the work in the *Malakowturm Julius Philipp*, the concept of 'sharing', and the friendship.

**My final conclusion:** This experience was inspiring, useful and I am grateful to be one of the visiting fellows in the Institute for Medical Ethics and History of Medicine in Bochum, Germany.

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## REPORT ON ICECC 2018

### The ICCEC 2018 conference in Oxford: an impression

This year's ICCEC conference 2018 was organized by the Institute of Medical Ethics (IME). The conference took place at the Mathematical institute of the University of Oxford in the beautiful city of Oxford in the UK. The theme was *Clinical Ethics in Translation: Linking Practice with Research, Learning and Policy*. After a welcome by Dr. Wing May Kong, we were immediately invited to reflect on the theme of the conference by three keynote speakers; Bobbie Farsides, Ross Upshur and Bert Molewijk, who all stressed the importance of ethics theory for clinical ethics yet approached the relationship between bioethical theory and clinical ethics support differently.

Also in the other plenary sessions, the theme of the conference was explored from different perspectives and angles. For instance on the second day, two plenary sessions from Alison Murdoch and Matt Kuczewski, took a clear normative stance on respectively mitochondrial donation and care for immigrants in the current US and nicely illustrated the obstacles they had encountered and policy steps they had taken on these issues. Finally, a very interesting plenary session was scheduled on the Saturday morning that was dedicated to empirical ethics, hosted by Anne Slowther. Both Mikey Dunn and Stella Reiter-Theil gave very interesting and complementary lectures which provided a nice overview of the complicated relationship between clinical ethics (support) and empirical research.

The parallel sessions presented, as usual, a varied mix of ethics support research, bioethical theory, experiences from health care workers, researchers and professionals providing ethics support. What I particularly liked was that there was symposium that examined racism in health care, titled: '*The color of medicine*': confronting the problem of racism in clinical settings' by Joel Wu, Nneka Sederstrom, Rachel Hardeman, Shelly Nauertz and Maurice Sholas. I think this is a serious, pervasive and under-researched

theme within clinical ethics. I am curious to see in what way both clinical ethics research and clinical ethics support can address and overcome the challenges of racism in health care.

In an interesting public session within the ICCEC conference, the audience was challenged to formulate their own normative views on a moral case regarding a boy that was mentally impaired and who on the one hand clearly resisted treatment but on the other hand was not able to formulate his viewpoint and oversee the consequences of his resistance. Elsewhere, the Joachim Schwager award was received by Dr. Joe Brierley from the Great Ormond Street Hospital, in London, UK. He developed a new Rapid Review (RR) Clinical Ethics Service to help children, their parents and clinicians in a children's hospital with a *rare disease focus* to decide whether to use innovative treatments in desperate situations.

Finally, the posters also provided food for thought. The most original idea during the poster sessions, in my opinion, was from the philosopher and clinical ethicist Jos Kole (Nijmegen, the Netherlands), who had duplicated a moral 'WhatsApp' conversation on his poster, and had made an app group in which the attendants of the conference were invited to continue the conversation with each other digitally. These innovative ideas and use of technological possibilities within clinical ethics support and education, and the ICCEC conference as a whole, really inspired me for my own practice: ethics support (research) and education in ethics at the Amsterdam University Medical Centres.

I thank the Institute of Medical Ethics (IME) and in particular Phil Greenwood for the excellent organization. I found ICCEC 2018 very inspiring: it is stimulating to hear about international experiences and research projects related to bioethics and clinical ethics support.

Looking forward to the next ICCEC conference in 2019 in Vienna!

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## THE OVIEDO CONVENTION CELEBRATES ITS 20TH ANNIVERSARY

### An Ethically and Legally Binding Source on Human Rights and Biomedicine\*

#### Aims and Objectives of the Conference

The Convention on Human Rights and Biomedicine (Oviedo Convention) marked the 20th anniversary in 2017 by an international Conference organized by the Council of Europe Bioethics Committee (DH-BIO) in Strasbourg, on 24-25 October 2017. The Oviedo Convention was produced for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine. Having been opened for signature for the first time on 4 April 1997 in Oviedo (Spain), this Convention is the only international legally binding instrument on the protection of human rights in the biomedical field. It draws on the principles established by the European Convention on Human Rights, in the field of biology and medicine.



It is a framework Convention aiming at protecting dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine. It sets out fundamental principles applicable to daily medical practice and is regarded as such at the European treaty on patient's rights. It also deals specifically with biomedical research, genetics and transplantation of organ and tissues. The provisions of the Convention are further elaborated and complemented by Additional Protocols on specific subjects (1).

#### Importance of the Oviedo Convention

\* An earlier version of this paper was presented as a poster: Ulman YI, "The Oviedo Convention celebrates its 20th Anniversary", *8th Cambridge Consortium of Bioethics Education*, Paris 6-8 July 2018.

In view of Dr. Roberto Andorno, “the importance of the Oviedo Convention lies in the fact that it is the first comprehensive multilateral treaty addressing biomedical human rights issues” and adds that “these rights have been developed and assembled in one single multilateral binding instrument entirely devoted to biomedical issues” (2). Since 1997, the Convention has been signed by thirty-five countries: Bosnia-Herzegovina, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Georgia, Greece, Hungary, Iceland, Italy, Latvia, Lithuania, Luxembourg, Montenegro, Netherlands, Norway, Poland, Portugal, Republic of Moldova, Romania, San Marino, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, The Former Yugoslavian Republic of Macedonia, Turkey, Ukraine; and ratified by twenty-eight countries (3). The United Kingdom and Germany remained absent due to different reasons. While the UK considered the Convention to be too restrictive, Germany viewed it to be too permissive, especially in the most controversial issues such as embryo research and non-therapeutic research on people unable to consent. (2).

*The Convention is binding* because States having ratified it are obliged to introduce implementing legislation to bring their national laws into conformity with its principles.

*It brings a comprehensive* approach to bioethics, by covering the whole domain of (human) bioethics as a multilateral treaty addressing the link between human rights and biomedicine.

*It is also a framework* instrument containing general principles to prevent practices that would infringe human rights and human dignity (2). Over the years, the additional protocols were produced on specific issues such as the Prohibition of Cloning Human Beings, the Transplantation of Organs, Tissues of Human Origin, the Biomedical Research, the Genetic testing for Health Purposes.

The Oviedo Convention brings *minimum common standards together* of biomedical activities on which there is a consensus among European countries. This minimalist approach arises from mere practical reasons. The agreement that has been reached has an important effect: introduce into their national law at least the common rules adopted.

The Convention brings *responsibility for the development and effective implementation at the national level*. State Parties are expected to take in their internal law the necessary measures to give effect to the provisions of this Convention.

The Convention's Article 23, regulates *judicial protection by national courts*. The States are required

to “provide appropriate judicial protection to prevent or to put a stop to an unlawful infringement of the rights and principles” set forth in the Convention.

The Oviedo Convention consists of a preamble and 28 articles, organized into 14 chapters. Concept of dignity, identity and integrity of human beings/individuals should be both the basis and the umbrella for all other principles and notions that were to be included in the Convention. Article 2 assigns the highest priority to the interests and welfare of the human being, whose respect “shall prevail over the sole interest of society or science”. The primacy of human beings means that no reason of economic efficiency or scientific progress can be used as a justification for an instrumentalization of people(2).

The Convention significantly elaborates the informed consent; explicit or implied, written or verbal consent; the value of advanced directives; right to privacy, right to know and right not to know; principles regarding genetics, predictive genetic testing, medically assisted reproduction and cloning; biomedical research, embryo research, organ donation and non-commercialisation of body parts (2).

### The Conference



The 20th Anniversary Conference was held under the auspices of the Czech Presidency of the Committee of Ministers of the Council of Europe and benefited from the outcome of the following activities:

High level seminar on “International case-law in bioethics: insight and foresight”, held on 5 December 2016, under the auspices of Cypriot Chairmanship of the Committee of Ministers

Study on “The rights of Children in biomedicine: challenges posed by scientific advances and uncertainties”, prepared by researchers from Uppsala University Department of Law (Sweden)

Study “From law to practice: towards a roadmap to strengthen children's rights in the era of

biomedicine", prepared by researchers from Leiden University Law School (the Netherlands). The Conference Speakers discussed the issues with keynotes (4), through an intense Programme (5).

### The Conference Report

The objective of this international Conference was to examine the relevance of the principles laid down in the Oviedo Convention with regard to developments in the biomedical field and possible human rights challenges raised by such developments.

The report, prepared by the Conference General Rapporteur, in cooperation with the rapporteurs of the different sessions, summarised the key points of the presentations and discussions. On that basis, it confirms the reference value of the principles laid down in the Convention at international level and underlines the areas for action proposed to address the challenges for human rights raised in particular by scientific and technological developments. All these elements will be used as a basis for the preparation by the Committee on Bioethics of the Council of Europe, in 2018-2019, of the Strategic Action Plan to respond to these challenges. (1).



### Conclusion

The Convention on Human Rights and Biomedicine is the first and only internationally binding legal instrument in the field of biomedicine. The Convention provides a "common framework for the protection of human rights and human dignity in both longstanding and developing areas concerning the application of biology and medicine.

The Convention acts as a reference document internationally and has had significant influence on legislation and practices at the national level, even in those Council of Europe Member States who have not signed and/or ratified the Convention. Indeed, the Convention is a beacon for the protection of human rights in the biomedical field outside the European

context. For instance, Mexico's membership is on the agenda (1).

A number of over-arching themes emerged during the course of the conference, including the increasing blurring of the boundary between medicine, research and the private sphere; the need to reconnect technologies to values and the necessity of public dialogue and deliberation in the regulation of scientific advances in the field of biomedicine.

Use of genomic data collected in the clinical context is increasingly being utilised for research purposes. Likewise, emerging technologies and NBIC (Nanotechnology, Biotechnology, Information technology and Cognitive technology) convergence enables the application of biomedical technologies beyond the medical sphere (6). One clear illustration of this point is the increasing use of biodata for nonmedical purposes for example, marketing. A key characteristic of the NBIC convergence is the gradual dissolution of the borders between the physical and the biological sciences. This raises the question of how to balance technological progress with human values and whether existing governance frameworks including the Convention on Biomedicine can deal with the ethical issues raised by the blurring of boundaries. Access to the benefits of scientific/technological advances needs to be grounded in the overarching principle found in the Convention, of the primacy of the human being and the protection of human dignity (1).

Convention recognised the inclusion of Article 32 which acknowledges the requirement for review of the provisions of the Convention in light of scientific developments. Genome editing technologies were discussed in this perspective. Article 13 of the Convention states "An intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modifications in the genome of any descendants." In October 2017 the Parliamentary Assembly of the Council of Europe adopted a Recommendation urging Member States to institute a national ban on establishing a pregnancy (as distinct from performing research on embryos and germlines) with germ-line cells or human embryos having undergone intentional genome editing (1).

The Recommendation also called for a broad and informed public debate in order to facilitate the development of Member State policies on the practical use of new genetic technologies. This debate should be informed by input from DH-BIO which can initiate a platform that enables Member States to reflect on policy and practice in this area (1).

The importance of the public debate was specifically reiterated throughout the conference. Combining the normative framework of human rights with scientific progress requires informed public dialogue; normative deliberations cannot remain limited to the expert level. The Nuffield Council on Bioethics in their report on emerging technologies advocated a 'public discourse ethics' approach to policy making and governance of such technologies. The Council suggested procedural virtues to foster this discourse including openness and inclusion, accountability, public reasoning, candour, enablement and caution.

The rights of children were dealt with at the Conference through the reports of Leifard et al and Zillen et al (7), (8). It was decided that to develop practical tools for both health professionals and parents to assist them in recognising children's evolving capacities and to facilitate children's involvement in decision-making affecting them. The particular vulnerability of inter-sex children were identified and the Parliamentary Assembly adopted, in 2017, a resolution on the rights of inter-sex children which called for the deferral of "sex-normalising" surgery until the child could participate in the decision (1).

The Conference Report ended by remarking the development of tools for participatory democracy, including the promotion of public debate on the ethical issues arising in the biomedical field (1).

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#### BOOK REVIEW

Roger Gil

#### **Les grandes questions de bioéthique Au XXI<sup>e</sup> siècle et dans le débat public**

Bordeaux : LEH Editions, 2018, 465 pages.

Roger Gil est un neuropsychiatre et bioéthicien de Poitiers. En se référant notamment aux valeurs dites républicaines, il publie une somme couvrant l'ensemble de la bioéthique : enjeux liés aux greffes d'organes, à la vie commençante et finissante, aux coûts de santé, aux directives anticipées en psychiatrie (à propos desquelles il évoque le pacte d'Ulysse), aux soins sous contrainte, à la recherche scientifique.

Chose à noter, l'auteur accorde un intérêt réitéré aux options théoriques et pratiques dans d'autres contextes. « Alors que les démocraties pluralistes s'accordent sur les droits de l'Homme, des divergences foisonnent qui surgissent de l'interprétation de ces valeurs. Cela peut donner l'impression d'un relativisme (...) Or, la pluralité doit être conçue comme une chance, du point de vue de la nécessaire tolérance et pour apprendre les exigences

de la délibération morale. » Démarche est potentiellement fructueuse. « L'attachement aux valeurs de la République nécessite plus que jamais qu'elles soient argumentées et confrontées à un nouveau mode de vivre ensemble. »

A propos de fin de vie, Gil a une grande crainte : « La légalisation d'une aide active à mourir introduirait une culture euthanasique à contre-courant de la culture palliative. Car il ne s'agira pas de limiter l'euthanasie aux échecs des soins palliatifs mais d'instituer, au nom de l'autonomie, un nouveau droit ». C'est là un postulat regrettable, avec lequel il convient de diverger au vu d'expériences ailleurs. En effet, même si les palliatologues ne sont pas unanimes, la tendance s'affirme qui montre que soins palliatifs et aide à mourir ne sont pas antagonistes ; ils peuvent être complémentaires, devant des soins palliatifs qu'on peut appeler intégraux.

Sur la procréation médicalement assistée, Gil parle de « confusion française », évoquant par exemple la paternité post-mortem, ainsi que la pénurie d'ovocytes - alors que le don est légal. Il discute la question aiguë de l'accès à ses origines, à propos duquel la France est en difficulté éthique et juridique croissante au plan international (maintien de l'accouchement sous X, anonymat des donneurs). A noter aussi la présentation de la saga des débats récents autour de la GPA (grossesse pour autrui) en France.

Intéressante position sur le spirituel dans la santé : « La spiritualité ne menace pas la laïcité puisqu'elle renvoie à la liberté de pensée dont se porte garant l'Etat. L'attention à la spiritualité est une nécessité éthique. Encore faut-il pointer le danger d'un amateurisme relationnel. La mission du soignant est de permettre aux besoins de s'exprimer et à la personne malade, si elle le souhaite, d'accéder à un aumônier. » Dernières lignes : « La méditation sur les valeurs impose de se sentir comptable d'une humanité angoissée par sa finitude, tourmentée par le mal commis et par le mal subi et qui doit tenter de ne pas céder aux mirages. »

*Les grandes questions de bioéthique* est un ouvrage richement informé et argumenté, équilibré, de lecture aisée.

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## THESIS

### Living with facial difference: an empirical-philosophical study

What does it mean to have a different face—a face marked by 'disfigurement'? My dissertation *Doing facial difference* (Maastricht, 2018) explores this question by means of an empirical-philosophical study into the lived experiences associated with facial difference. On the one hand, this study draws on interviews with individuals who lost part(s) of the face and wear a facial prosthetic device ('facial prosthesis'). On the other, the study's design and analysis mobilize various (critical) theories on embodiment, assistive technologies, and disability. Below, I introduce the background and approach of my thesis, after which I discuss my findings and conclusions.

#### Background

While conditions associated with the loss of part(s) of the face have received little scholarly attention, there exists a moderate body of literature into 'facial difference'. This literature generally takes either a medical approach or a psycho-social one. Having an atypical face, however, does not only involve medical or psychosocial issues. It also involves affected individuals' lived experiences: the subjective, direct manner in which they experience their altered face in the context of day-to-day life. Indeed, as researchers working in the field of the phenomenology of illness and disability have demonstrated, health conditions impact how affected individuals relate to their own body, daily objects, other people, and their surroundings (see, for instance, Toombs 1988, Svenaeus 2015, Carel 2016). By investigating the lived experiences of those who have an atypical face, my thesis complements medical and psycho-social approaches to facial difference. By focusing on the experiences of those who have lost part(s) of the face, it adds a new angle to the study of 'disfigurement'.

#### Approach

To explore the lived experiences associated with facial difference, I conducted in-depth, semi-structured interviews with twenty individuals, twelve of whom were men and eight women. Respondents were between ages 42 and 84 at the time of the interviews. They all lost part(s) of the face (nose, eye socket, or a larger facial area) to either cancer or an accident. To hide their facial difference from view, they make use of a facial prosthesis, or various types of covers such as gauze dressings, Band-Aids, or eye-patches. Participants were recruited through a prosthetics service facility operating within a medical center located in a large city in the Netherlands. In addition to these interviews, I performed observations in the

medical center itself, as well as in three different prosthetics service units in the Netherlands and Belgium.

Analyzing the data, I followed the method of thematic analysis (Braun & Clark 2006). I also took direction from interpretative phenomenological analysis (IPA), a qualitative approach that puts special emphasis on the ways individuals make sense of their own subjective experiences, in particular following a life-changing event (Smith, Flowers, & Larkin 2009). My analysis of the interviews was also informed by an ongoing reading of key texts in phenomenology, postphenomenology, and disability studies. Each of these approaches helped pinpoint distinct aspects of the ways in which interviewees experience and relate to their facial limb absence in everyday life. These aspects include the fundamental corporeality of human existence, the way illness or disability affect this embodied-being-in-the-world, the role of medical aids—such as prostheses—herein, and the effect of disability societal norms on everyday social interactions.

#### **Findings: relating to an altered face and world**

As I found while analyzing the interviews, respondents confront various sensorial impairments and uncomfortable sensations after losing part(s) of the face. Those who lack an eye socket may have problems perceiving depth and often have a limited visual field. Participants who lost a nose may have trouble smelling and tasting. Most interviewees also have numbed facial areas that cannot perceive touch or movement. And many regularly experience troublesome pain, itching or phantom sensations in the affected facial area, as well as dryness or mucus leakage.

In addition to these functional problems, respondents also encounter issues due to their altered appearance—following from the absence of part(s) of the face, as well as from the visibility of the covers they wear to hide this absence from view. In public locations, participants' unusual looks mean that they frequently confront staring gazes, questions, and (offensive) remarks from strangers. As a result, they report, they may feel self-conscious, ashamed, or inferior. But such unwanted attention is not only awkward; it also means that interviewees are rarely anonymous in a crowd. This means their ability to inhabit and move through public spaces is hindered. The visibility of their facial difference also plays a role in the privacy of their home. Some (eventually) feel at ease about 'uncovering' their face to their intimates (partners and family members, friends), indicating this makes them feel accepted for who they are. Others take care to always keep their 'disfigurement' hidden, because they or their intimates are uncomfortable with the sight it presents.

Unwanted attention, my analysis discloses, can often be avoided by wearing a facial prosthesis. This device is much less conspicuous than visible covers such as gauze dressings, Band-Aids, or eye-patches. By emulating the appearance of the lacking facial area, facial prostheses in fact 'recover' respondents' face. As a result, when carrying their prosthesis participants often manage to 'pass as normal' and thereby evade others' notice. Still, others may sometimes 'discover' the device's artificiality. This may happen, for instance, when another person is standing in close proximity to the prosthesis' user, when the artificial limb is misaligned, when its edges gape, or when it fails to color along with a blush or a summer tan. In such an event, stares, questions and remarks are often quick to follow.

These changes mean that respondents regularly experience difficulties while undertaking everyday projects. Riding a bicycle, stacking objects, playing music together with others, eating, kissing, taking the bus, sitting in a café with friends—these and other daily activities are all complicated by sensory impairments, uncomfortable sensations, or a visibly different appearance. But the participants in my study do not undergo these difficulties passively. Instead, they adjust to their altered face by gradually (and mostly intuitively) developing new (bodily) habits. They learn to walk differently to keep from tripping. They no longer chew on the numb side of their face to avoid the unpleasant sense of alienation this evokes. They learn to endure pain, itching, or uncomfortable phantom sensations. They camouflage their prosthesis to make 'passing as normal' more likely, and take care to prevent the device from touching another person's face during a kiss. And they learn how to manage others' unwanted attention.

#### **Conclusion: doing facial difference**

Losing part(s) of the face, I conclude, signals a radical shift in how affected individuals inhabit their body and world because both have become less familiar and accommodating. Their newly developed habits are not simple adjustments. Rather, they embody an altered relationship to one's face and world. These habits, I argue, are ways of 'doing' the different face. But doing facial difference is not done all by itself; it requires continuous, daily efforts.

By offering a detailed and practical understanding of the everyday meaning of the loss of part(s) of the face, my findings may help patients handle the challenges they (stand to) encounter. These findings may also help healthcare practitioners improve the information, care, and support they offer patients. Finally, my findings offer insights into fundamental issues such as the nature of the human face, the function of prostheses, the dynamics of immediate social interactions, the role of visibility in our lives, and the meaning of difference.

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**DEADLINE NEXT NEWSLETTER**

The deadline for the third edition of 2018:

**November 15, 2018**

If you wish to promote your event, or to inform your EACME-colleagues about the results of your work, descriptions of projects, book reviews etc. Any good ideas for the upcoming edition?

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