

# Planning Later Life

Bioethics and Politics  
in Aging Societies

July  
10<sup>th</sup> – 12<sup>th</sup>  
2013

Göttingen

-Abstracts-

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**Willibald J. Stronegger, Nathalie T. Burkert, Franziska Großschädl and  
Wolfgang Freidl**

(University of Graz, Institute of Social Medicine and Epidemiology)

Factors associated with the rejection of active euthanasia among the general public in Austria

Background: In recent years, the Netherlands, Belgium and other European countries have adopted laws allowing physicians to provide so-called active voluntary euthanasia (AVE) in certain cases. This means that the life of terminally ill persons may be shortened according to their own wishes. The primary purpose of this study was to survey the current attitude towards active voluntary euthanasia within the Austrian population and to identify explanatory factors in the areas of socio-demographics, personal experiences with care, and ideological orientation.

Methods: A cross-sectional study, based on telephone interviews (CATI), was conducted among 1,000 individuals aged 16 years and over that were selected as representative of the Austrian population. For the purpose of measuring attitude toward active voluntary euthanasia, two different problem formulations (abstract vs. situational) were juxtaposed.

Results: The abstract question about active voluntary euthanasia was answered negatively by 28.8%, while 68.8% opted in favour of AVE or were undecided. Regression analyses showed rejection of AVE increased in connection with increasing numbers of adults and children in the household, increasing experience with care of terminally ill persons, a conservative worldview, and increasing levels of education. Higher family income was associated with lower levels of rejection. No independent correlations were found for variables such as sex, age, political orientation, self-rated health, and experiences with care of terminally ill patients. Correlation for the situational problem formulation was weaker and included fewer predictors than for the abstract question.

Conclusion: The results support the hypothesis that the attitude toward AVE is mainly marked by ideological convictions and less so by personal experience with human suffering. Furthermore, the results suggest that comparably higher rejection of AVE is associated with being part of primary social networks and of traditional, conservative value systems.

## Planning Later Life –

### Bioethics and Politics in Ageing Societies

July 10<sup>th</sup> – 12<sup>th</sup> 2013

Paulinerkirche / Heyne-Haus  
Papendiek 14 & 16, 37073 Göttingen

#### Organized by

Silke Schicktanz & Mark Schweda (Medical Ethics and History of  
Medicine, University Medical Center Göttingen) & Frank Adloff  
(Sociology, University Erlangen-Nürnberg)

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## PROGRAM

### Wednesday, July 10<sup>th</sup> 2013

6.15 pm WELCOME ADDRESS:

Hiltraud Casper-Hehne  
(Vice President Georg-August-University Göttingen)

PUBLIC KEYNOTE LECTURE:

### **Norman Daniels**

**(Harvard, Department of Global Health and Population)**

### **A Lifespan Approach to Intergenerational Equity**

THURSDAY, JULY 11<sup>TH</sup> 2013

9.00-9.15	<b>Opening Remarks</b>		
<b>Panel I: Old Age Between Autonomy and Dependency</b>			
9.15-11.15	<ul style="list-style-type: none"> <li>▪ <i>Thomas Rentsch</i> (University of Dresden, Institute of Philosophy): <i>Aging as Becoming Oneself. A Philosophical Ethics of Late Life</i></li> <li>▪ <i>Paul Higgs</i> (University College London, Mental Health Sciences Unit): <i>Towards a Sociology of the 'Fourth Age'</i></li> <li>▪ <i>François Höpflinger</i> (University of Zurich, Institute of Sociology): <i>The 'Young Old' and the 'Old Old': Conflicting Social Cultures in Later Life</i></li> </ul>		
11.15-11.45	<b>Break</b>		
11.45-13.15	<b>Sessions I</b>		
	<b>A. Autonomy and Dependency in Medical Decision Making and Care</b>	<b>B. Healthcare and Planning for Later Life</b>	<b>C. Advance Directives and End-of-Life Decision Making</b>
	<i>Noelia Bueno Gomez (Oviedo)</i> <i>Autonomy Versus Dependency in the Old Age: A Reconsideration from a Narrative Conception of Personal Identity</i>	<i>Michael Coors (Hannover)</i> <i>Imagine a Life ... The Impact of Imagination on Ethical Decisions</i>	<i>Kai Brauer (Feldkirchen)</i> <i>Final Decisions for the Final Crisis. Hopes and Hypes of the Advance Directive in Germany</i>
<i>Helena Hermann, Manuel Trachsel, Nikola Biller-Andorno (Zürich)</i> <i>The Dual Process Model of Information Processing in Medical Decision-making Capacity</i>	<i>Julia Inthorn (Göttingen)</i> <i>Age as Normative Argument? Lay Persons Perspectives on Medical Decisions in an Intercultural Comparison Between Germany and Israel</i>	<i>Claire Rommelaere (Namur)</i> <i>Mental Disorders and Advance Directives About Healthcare. Responses of Belgian Law to a Future Incapacity to Make (One's Own) Decision</i>	

Hsiu-I Yang

(University of Taipei, Institute of Public Health)

A Shifting Paradigm from Presumption for Life to Presumption for Peaceful Death for the "old-old" and "very-old" elderly

It is for sure that we all will die, but it's not sure if we will be fortunate enough to live to old age and then have a peaceful death, a desirable situation described by an old Chinese idiom "End of long life and die in sleep" (壽終正寢). Thanks to public health measures and a higher standard of living, men and women in developed countries nowadays have a historically highest average life expectancy up to and over 80 years old. It is predicted that, by the year 2045, 95% of death will occur between the age 77 to 93, and the average death age will be steadily at 85 years old. For those old-old (75-85) and oldest-old (over 85) people, having complete a full life, it is rational to presume that a peaceful death is something in themselves and their family's expectation. Nonetheless, such wish is often interrupted by the established paradigm for saving life. Following ethical and legal (including human rights) principles, decisions concerning potentially life-prolonging treatment must start from a presumption in favor of prolonging life. This presumption will normally require doctors in ER to take all reasonable steps to prolong a patient's life, no matter how old he/she is. This paper argues for a shifting paradigm from the "presumption is for life" to for peaceful death for people over 75. In this group of people, instead of assuming that a now incompetent patient would want to receive treatment and care in the absence of clear evidence to the contrary, the assumption should become that since any "reasonable" person over 75 would want to exercise a "right to die," treatment and care should be withheld or withdrawn unless there is evidence to the contrary. This new paradigm will have three advantages. First, it may encourage all the senior citizens and their adult children to talk about life-death decisions frankly and honestly. Secondly, it may avoid painful and futile life-saving procedures and facilitate dying in dignity. Finally, this new paradigm integrates the seemingly conflicting concept of "death" into "life," because a good life includes a good death.

**Harish Naraindas**

(University of New Dehli, Centre for the Study of Social Systems)

Medicine, Magic and Religion: Planning Later Life through a Panoply of German Therapeutic Practices

This paper is based on a retrospective narrative of a 70 year old domiciled Dutch person's bi-annual sojourn at an Ayurvedic Kur Klinik near Göttingen. It will hope to demonstrate through his narrative that *planning later life*, although squarely situated within the realm of *medicine*, requires of us to interrogate and enlarge the scope of what constitutes medicine, especially in the German context. An interrogation that may lead to the blurring of the distinction between orthodox and heterodox medical practices, Eastern and Western medicine, and the well-worn distinction between (scientific) medicine, magic, and religion. This diversity, and the crossing of boundaries between epistemic, ontological and metaphysical realms, is best captured by the term *panoply*. Panoply seemingly signals, in the current post-reformation and post-sacramental world, a form of plenitude, which in a therapeutic context would be a long list, or an impressive array, of therapeutic forms, drugs and devices to keep adversity at bay, best summed up by its older meaning of a protective suit of armour. But this older meaning of a protective suit of armour was not merely to keep adversity at bay but to keep the Adversary at bay (c.f. Ephesians: 6. 11-14). This paper will demonstrate how *planning later life* often involves the intertwining if not the mangling of these registers or realms, how this is probably more true to form in terms of persons lived lives, and how persons/patients *and* practitioners need to summon everything at their disposal to help cope with ageing, dissolution and impending death.

	<i>Clara Berridge (Berkeley)</i> <i>Subjecting One's Self to Monitoring: Decision Making About the Option to Use Remote Monitoring Technologies in a Low-income Independent Living Residence</i>		<i>Ralf J. Jox (Munich)</i> <i>Advance Refusal of Treatment and Organ Donor Cards: An Ill-Matched Couple?</i>
<b>13.15-15.00</b>	<b>Lunch Break / Guided City Tour (1h)</b>		
<b>Panel II: Evidence and Benefits of Prevention and Prolongevity</b>			
<b>15.00-17.00</b>	<ul style="list-style-type: none"> <li>▪ <i>S. Jay Olshansky (University of Illinois at Chicago, School of Public Health): Attacking Diseases by Slowing Aging</i></li> <li>▪ <i>Søren Holm (University of Manchester, Center for Social Ethics and Policy): Not Growing Old – Gracefully?</i></li> <li>▪ <i>Frank Adloff (University of Erlangen-Nürnberg, Department of Sociology): Paradoxes of Planning Later Life: Anti-aging Practices and the Lived Body</i></li> </ul>		
<b>17.00-17.30</b>	<b>Break</b>		
<b>17.30-18.30</b>	<b>Sessions II</b>		
	<b>A. Prevention and Health Responsibility</b>	<b>B. Anti-Aging and Life Extension</b>	<b>C. Images of Ageing, Dependency Finitude</b>
	<i>Tobias Eichinger (Freiburg)</i> <i>Prevention of What? Ethical Aspects of the Medicalisation of Aging</i>	<i>Robin L Pierce (Delft)</i> <i>Synthetic Biology in Molecular Medicine: Forging a New Relationship Between Aging and Disease?</i>	<i>Claudia Bozzaro (Freiburg)</i> <i>Aging Between Autonomy and Vulnerability</i>
	<i>Larissa Pfaller (Erlangen-Nürnberg)</i> <i>From Users to Adherents – Anti-aging as a Way of</i>	<i>Mark Schweda (Göttingen)</i> <i>When I'm 640. Prolongevity and the Ethics of the</i>	<i>Antony Pattathu (Heidelberg)</i> <i>Narratives of Aging and Death: The Representation of</i>

	<i>Life. Qualitative Interviews and Biographical Perspectives</i>	<i>Human Life Course</i>	<i>Aging and End-of-life Rituals in Popular Fiction Films. The Case of Morrie Schwartz</i>
<b>20.00</b>	<b>Conference Dinner</b>		

**FRIDAY, JULY 12<sup>TH</sup> 2013**

<b>Panel III: Personal Identity and Dementia</b>			
<b>9.00-11.00</b>	<ul style="list-style-type: none"> <li>▪ <i>Perla Werner</i> (University of Haifa, Faculty of Social Welfare&amp;Health Sciences): <i>Competence, Like Truth, Beauty and Contact Lenses, is in the Eyes of the Beholder: Ethical Issues and Cognitive Deterioration</i></li> <li>▪ <i>Dieter Sturma</i> (University of Bonn, Department of Philosophy / German Reference Center for Ethics in the Life Sciences (DRZE)): <i>Autonomy and Personal Identity Over Time. The Challenge of Dementia</i></li> <li>▪ <i>Silke Schicktanz</i> (University of Goettingen, Department for Medical Ethics and History of Medicine): <i>We Are Many! The Role of Alzheimer Advocacy Groups for Public Bioethics</i></li> </ul>		
<b>11.00-11.30</b>	<b>Break</b>		
<b>11.30-13.00 Sessions III</b>			
	<b>A. Autonomy and the Demented Self</b>	<b>B. Recent Developments in Dementia Research</b>	<b>C. Mental Health &amp; Cognitive Enhancement in Old Age</b>
	<i>Chiara Cerri</i> (Madrid) <i>The Sickness in Old Age: New Strategies of Care</i>	<i>Bert Heinrichs</i> (Bonn) <i>Informed Consent in Dementia Research</i>	<i>Saskia K. Nagel,</i> <i>Thorsten Moos,</i> <i>Magnus Schlette,</i> (Osnabrück/ Heidelberg)  <i>„Train Your Brain for Active Ageing“ – Studying the Imperative of Self-Determination in High Age</i>

**Peter Derkx**

(University of Utrecht, Institute for Humanist Studies)

Ethical evaluation of research funding for substantial life extension

Since 1995 genomics, genomics-based pharmaceutical research and stem cell research have changed the aim of biomedical gerontology from description of age-associated diseases to explanation, treatment and prevention of the underlying processes of senescence. Some scientists have even started to view aging itself as a disease. The ethical question arises whether large amounts of money should be invested in research aiming at decelerating or stopping processes of senescence (or at regular intervals repairing the damage done by those processes) in order to make possible healthy and vigorous lives of more (or even much more) than a hundred years on average.

Ethical arguments of beneficence (well-being), autonomy (freedom), distributive justice and a meaningful life will be reviewed and evaluated.

Main conclusions are:

- It is very difficult if not impossible to distinguish between curing and preventing age-associated diseases and making people live as long as possible.
- In principle there is nothing morally wrong with attempts at substantial life extension.
- However, as important as the question whether substantial life extension should be permitted or not, is the question whether it deserves high priority.
- Population growth will be a problem, but to a large extent this is more a problem of ecology, environment and life style than of birth and mortality rates.
- Population aging and age-associated diseases are not a luxury problem of developed countries in the Western or Northern part of the world. So-called developing countries in the South will have enormous numbers of elderly persons within a few decades.
- Fighting socially determined inequalities in health and life expectancy (between countries and within) deserves a high priority. It can be regarded as not only a morally recommendable but also as a very effective form of life-extension.

repeated and multi-organ donation should be available to younger persons rather than elderly recipients.

Conclusion: Affected persons do not consider age to be a criterion for disease. However, those affected regard biological age as an argument against living donation because young prospective donors are conceived of as needing protection, yet elderly family members, too, should be protected considering potential risks. Those affected by living organ donation reflect on medical feasibility as they themselves have benefitted from it. They are positive about these technologies but by no means uncritical as they also bring up the questions of regulation and rationing in old age.

	<i>Irmela Krüger-Fürhoff (Berlin)</i> <i>'Speaking as,'</i> <i>'Giving Voice to,'</i> or <i>'Talking on Behalf of' People with Dementia. Ethical and Aesthetic Challenges of Narrating Alzheimer's Disease</i>	<i>Fred Ketchum (Chicago)</i> <i>Early Treatment is the Best Treatment: Normalizing Cognition Through Clinical Trials</i>	<i>Susanne Dungs (Feldkirchen)</i> <i>Cognitive Enhancement in Aging Societies</i>
	<i>Shelley L. Kobuck (Duquesne)</i> <i>The Ethical Justification of Research with Advanced Stage Dementia Patients in the Context of Self-Determination</i>	<i>Yvonne Cuijpers (Utrecht)</i> <i>What's News? Social and Cultural Implications of Early Diagnostics for Alzheimer's Disease</i>	
<b>13.00-15.00</b>	<b>Lunch Break</b>		
<b>15.00-16.00</b>	<b>Sessions IV</b>		
	<b>A. Healthcare in Aging Societies</b>	<b>B. Public Policy in Aging Societies</b>	<b>C. Death and Dying in Aging Societies</b>
	<i>Andrea Vermeer (Erlangen-Nürnberg)</i> <i>The Role of Constructive Conflict Regulation for a Holistic Health Approach – Elder Mediation</i>	<i>Peter Derkx (Utrecht)</i> <i>Ethical Evaluation of Research Funding for Substantial Life Extension</i>	<i>Hsiu-I Yang (Taipei)</i> <i>A Shifting Paradigm from Presumption for Life to Presumption for Peaceful Death for the "Old-old" and "Very-old" Elderly</i>
	<i>Sabine Wöhlke (Göttingen)</i> <i>Age as a Criterion in Living Organ Donation</i>	<i>Harish Naraindas (New Delhi)</i> <i>Medicine, Magic and Religion: Planning Later Life through a Panoply of German Therapeutic Practices</i>	<i>Willibald J. Stronegger, Nathalie T. Burkert, Franziska Großschädl, Wolfgang Freidl (Graz)</i> <i>Factors Associated with the Rejection of Active Euthanasia Among the General Public in Austria</i>

<b>Concluding Lecture:</b>	
<b>16.00-16.45</b>	<i>Andreas Kruse (Institute of Gerontology, University of Heidelberg): Vulnerability and Developmental Potentials in Border Situations: To a Comprehensive Understanding of Very Old Age from an Individual, Cultural and Political Perspective</i>
<b>16.45-17.30</b>	<b>Concluding Remarks</b> <ul style="list-style-type: none"> <li>▪ <i>Norman Daniels (Harvard)</i></li> <li>▪ <i>Silke Schicktanz (Göttingen)</i></li> <li>▪ <i>Frank Adloff (Erlangen-Nürnberg)</i></li> </ul>
<b>From 19.00</b>	<b>Final Party</b>

### **Sabine Wöhlke**

(University of Göttingen, Department for Medical Ethics and History of Medicine)

#### Age as a Criterion in Living Organ Donation

Background: Organ donation, especially living organ donation, has a high societal relevance in Germany. Although the number of living organ transplants has increased between 1990 and 2011 from 40 to 795. In living organ donation the organ of a relative is applied for medical intervention. This gives rise to classic questions about the body and age in the face of new possibilities in modern medicine regarding urgency and rationing. In 1999 Eurotransplant started a Senior Program, which is also known as the "old for old"-program, in which donors of 65 years or older are allocated to recipients of the same age group, without taking into account the tissue characteristics. Organ transplantation changes the „traditional“ boundaries between the inside and outside of human bodies and challenges affected persons to rethink the meaning of these possibilities and boundaries regarding the criterion of 'age'.

Methods: The socio-empirical study consists of 27 semi-structured interviews and six focus group discussions of German recipients and donors of living kidneys conducted in 2009-2010 (N= 47). The sample consists of a broad spectrum of kidney donors and recipients with different kinds of social and biological relationships.

Aim: My investigation aims at the qualitative, cultural and ethical analysis of the conditions under which those affected by a living organ donation (donor and recipient) consider age as a criterion.

Results: Initially, those affected by living organ donation are motivated by the criterion of immediate ‚affectedness‘ (this includes relatives), rather than age.

Empirical results show three main foci:

1. Prognosis and prevention: those affected emphasize the significance of different age groups and the need for adapting information on a preventive life style to the respective age groups because of their different priorities (e.g., a healthy diet)
2. Allocation of resources (contexts of allocation): for those affected, age is very important in the acceptance of organ donation; also, biological age or age-related (physiological) norms are considered to be important in organ donation.
3. Prolonging life (future scenarios): Those affected regard old age as an important limiting criterion for life prolonging treatment. Thus, e.g.,



**Andréa Vermeer**

(University of Erlangen-Nürnberg, Department of Theology)

The Role of Constructive Conflict Regulation for a Holistic Health Approach -  
Elder Mediation

Following a holistic approach of the aging process, the method of *Elder Mediation* deals With key Issues such as: dependence of an elder person on family members, paid caregivers, hospital staff, care representatives. During the aging process the social environment is changing, accustomed procedures have to be abandoned, social networks disappear. Consequently, conflicts appear in various stages with family members, hospital staff or residents of a home.

In order to address the myriad of changes, *Elder Mediation* wants to facilitate the discussion by involving often a large numbers of people – predominantly family members--- who are concerned or affected by the aging process of a person.

The method of mediation itself is rarely subject to research, and therefore, needs more empirical and theoretical evidence on alternative conflict regulation processes to get theory based facts to develop sustainable implementations.

This presentation draws attention to the importance of conflict regulation in this special environment of elder people, taking under consideration the scientifically proven correlation between health risks and stress symptoms’ appearing in conflict situations.

**Norman Daniels**

(University of Harvard, Department of Global Health and Population)

### A Lifespan Approach to Intergenerational Equity

A key premise of this conference is that there must be appropriate planning for societal aging and the emergence of more controversy around intergenerational equity. How should we design institutions that treat different generations in a just way? An approach to such a design is sketched in this paper. Societal aging is the result of the success of public policy in reducing mortality and fertility rates, but even with the compression of morbidity, the societal profile of needs changes and with societal aging, intergenerational equity issues are sharpened. Some three decades ago I distinguished two issues of "intergenerational equity," equity between age groups and equity between birth cohorts. A successful policy must address both issues at once. I propose a Prudential Lifespan Account that addresses the age group problem and may be combined with a rough solution to the birth cohort problem, but the approach has important limitations. Since, as I have emphasized since first sketching this approach, prudence cannot in general address justice between persons, we must use a highly constrained notion of prudence and we must in any case assume that interpersonal problems of justice are already addressed. In any case, prudence in this approach is best viewed as a heuristical guide to thinking about the tradeoffs of services across stages of life, not as a blueprint for calculating what services to provide when. The account, however limited, is defended against various objections. In any case, it faces a serious problem in helping us think about intergenerational justice in societies in which population is shrinking.

**Susanne Dungs**

(University of Kärnten, The School of Health and Social Science)

### Cognitive Enhancement in an Aging Society

The range of neuro-enhancers (so-called "smart drugs") increases because the pharmaceutical industry has discovered this market for itself and is working hard on agents that are to be taken not only in the context of medical treatment (for example of neurodegenerative diseases), but can also be used on the basis of a flat side-effect profile as psychopharmaceuticals for the purpose of so-called neuro-cognitive enhancement or enhancements. This non-medical use of psycho-pharmacological drugs is called an "off-label use." The "off-label use" results not only from extending the medicalization to the principally healthy people but also from the change in the images of man, making the corridor of persons socially regarded as "normal" and "healthy" increasingly narrow. The ethical debates about the cognitive enhancement or neuro-enhancement have started in Germany with some delay compared to the Anglo-American countries, drawing into attention a striking entanglement with developments in old-age research. "Similar to the debates on enhancement and neuroscience concepts such as 'successful aging' have spread since the 1980s forming a new gerontology (Rowe & Kahn, 1998) which was paradigmatic for the development of old-age research" (Bülow 2012: 270). The images of an active and successful aging seem to correspond with the social development of an "optimized human being". This may also be valid for the images of an attentive and efficient childhood (visible for example in the field of ADHD problems). This paper examines firstly the parallels of structure of cognitive enhancement in the life phases of age and childhood. Secondly, it integrates this life phase related debates in the contemporary discourses on the improvement of the human condition (up to the post and transhumanist movement). Of particular interest are the explicit and implicit normative implications which obviously support current images of aging and childhood. In both life phases a materialistic conception of the human psyche seems to come to the fore, which is in turn supported by the Neurosciences.

**Saskia K. Nagel, Thorsten Moos and Magnus Schlette**

(University of Osnabrück, Institute of Cognitive Science/ University of Heidelberg, Institut for Interdisciplinary Research)

„Train Your Brain for Active Ageing“ – Studying the Imperative of Self-Determination in High Age

The last years have seen a growing focus on ageing in life sciences, humanities, social sciences, but also in popular discourse, self-help literature, and political discussion.

The shared credo is that ageing can and should be planned and shaped. Here, the neurosciences play an important role in feeding the discussions about how to provide preventive strategies to allow „successful ageing“, and how to train the brain to stay healthy and capable in high age. Notably, findings about the brain’s plasticity foster the extension of the imperative of selfdetermination that is omnipresent in individualistic societies, to caring for one’s brain and using its potential to the fullest. The elderly are expected to engage in training, nutrition, and exercise programs to delay the transition between third and fourth age, and to live an active and satisfying life till the end. Self-design during the whole lifespan appears to be societally expected and mirrors expectations of productivity and self-determination. The apparent ideal of selfdetermination is at the normative core of modern individualism. We scrutinize the imperative of self-determination from perspective of the neurosciences, social sciences, and humanities. It is studied how the results of the neurosciences concerning „brain anti-ageing“ enter (1.) the individual’s understandings of self-shaping and self-determination, (2.) the discourse on “good“ or “successful ageing“, and (3.) the debates on public health and prevention. A historical parallel to the prevention discourse in 1920’s Europe will shed light on the intricately intertwined relation of science, politics, and the self-formation of individuals in medical contexts. Thus, as the focus on individualization in high age supposedly has consequences for social policy, e.g. in insurances

that consider preventive measures, a timely discussion of the potential and limits of self-design is necessary and should be done with interdisciplinary expertise.

**Thomas Rentsch**

(Dresden University of Technology, Institute of Philosophy)

Aging as Becoming Oneself. A Philosophical Ethics of Late Life

Enlightenment and modernity have forgotten old age in constructing an abstract ethics of reason, addressing a general rational subject. By contrast, the ancient ethics of happiness asked what a good life might be for people in specific lifestages, such as the aged. It is nowadays important to regain this tradition: What does it mean for a finite being to age but still lead a good life? During the process of aging, a radicalization of our vulnerable corporality and finitude takes place. This becoming-oneself-in-aging can be understood not only in its ethical meaning, but also implies a correction of our modern understanding of man.

**Paus Higgs**

(University of London, UCL Mental Health Sciences Unit)

**Towards a Sociology of the Fourth Age**

Conventionally the sociology of old age has treated the final stage of the life course as a 'residual category' of social and health policy, having little autonomy from the structuring processes of modernist institutions and individual biographies. As such it has received relatively little sociological theorising. In recent decades this lacuna has been challenged by both the de-standardisation of the life course and the emergence of the third age. This latter development has been the subject of a number of theoretical interventions which have established it as a way of understanding some of the coordinates of contemporary later life. Less attention, however, has been paid to the other constituent part of the re-articulation of modern old age namely the 'Fourth Age'. While this phenomenon has its roots in the discourses surrounding the dependency and decline of old age, in contemporary circumstances it becomes much more than a final stage of life. In the circumstances of the agentic cultures of the third age, longer and healthier later lives as well as their associated lifestyles, the Fourth Age acts as a 'social imaginary' for a feared old age of dependency and decline. The impact of this social imaginary can be observed in its effects on people of all ages, from the young who seek to minimise their potential ageing to the retired who wish to show that they are still capable of the agency that marks out the third age. In part this is a recognition of the fact that those who come to be defined (or assessed) as being in this category have passed into a category of 'ageing without agency' and are deemed through social and health policies to be sequestered from everyday life. This paper will argue that there is a need to study the Fourth Age sociologically.

**Yvonne Cuijpers**

(University of Utrecht, Institute of Sustainable Development)

**What's News? Social and Cultural Implications of Early Diagnostics for Alzheimer's Disease**

In the light of this conference to reflect on the relevance of modern medicine in shaping the lives and situations of aging and elderly persons, I would like to address the social and cultural implications of early molecular diagnostics of Alzheimer's disease (AD).

How to assess the social and cultural implications of early diagnostics for AD? This is not an easy question, early diagnostics are emerging (partly functioning, partly promises), Alzheimer's disease is something else where ever you look for it (policy, nursing home, memory clinic, patient support groups), and different futures are aimed for (e.g. find a biomedical solution, deal with growing number of patients with dementia, provide proper care, deal with this changing condition in daily life, etc.). Also assessing (estimating what will happen, valuing, and judging) can greatly differ.

I have studied how this is being done in so called 'alzheimer cafés', in a formal health technology assessment, and in newspaper articles. For this presentation we focus on the articulations in Dutch national newspapers.

Early diagnostics strengthens specific conceptualizations of AD and images of the future, and is being shaped by them at the same time. We systematically investigate the following questions: (i) what is the role of early diagnostics? (ii) what futures of AD are addressed? (iii) how is AD conceptualized? We will show that early diagnostics play multiple roles (e.g. as innovation, as step in a development trajectory for medication, as patient information, as a weapon in the battle against the problems of our aging society, as a verdict for person and his relatives), and is connected to different articulations of the future, and conceptualizations of Alzheimer's disease.

**Fred Ketchum**

(University of Chicago, Department of Anthropology)

**Early Treatment is the Best Treatment: Normalizing Cognition through Clinical Trials**

This paper describes changes in clinical trials of therapies targeting Alzheimer's disease, to show how these processes are normalizing different standards for cognition. Currently no treatment exists for the ever growing numbers of Alzheimer's patients, though by many accounts the best hope for an effective treatment lies in continued research efforts and clinical trials of vaccine immunizations, which target the "plaques and tangles" believed to cause the disease. In the course of the past decade, developments in research and vaccine clinical trials have continually shifted the optimal point at which Alzheimer's treatment should be started earlier: ideally, treatment should begin for at risk patients in preclinical states when patients have very few symptoms. This has led to the expansion of trials for pre-dementia (i.e. MCI) patients, and hopes for even earlier interventions, when patients do not yet have visible symptoms. Drawing on ethnographic fieldwork at a memory clinic, I describe the how the kinds of clinical trials conducted have shifted, justified by a broadening notion of risk. I explore the consequences that moving the optimal point of effective intervention into late middle-age has on concepts of what counts as normal aging and cognition, to place these changes in relation to more broadly described trends of anti-aging in medicine. I conclude by considering the ethical consequences of these shifts in treatment models have on the self-understandings and experiences of those in latemiddle age (who fear their cognition may be affected), and their interest in seeking potential treatments in clinical trials.

**François Höpflinger**

(University of Zurich, Institute of Sociology)

**The 'Young Old' and the 'Old Old': Conflicting Social Cultures in Later Life?**

The combination of demographic ageing and new models of ageing results in historically new dynamics of later phases of life. This is particularly the case for younger cohorts of elderly persons; cohorts of women and men having internalized an active life-orientation and individualized life-styles. Active ageing, productive ageing and successful ageing are concepts used to describe new forms of ageing (for new generations). The so-called 'old young' or socially more acceptable the 'young old' lead – due to better health and for some groups greater affluence – a more active retirement than earlier generations.

The trend toward an active phase of ageing – among the 'young old' - reinforces, however, anxieties about the risks of high age. Adaptation to functional and cognitive impairments is more difficult after a long period of healthy ageing and to become dependent on the care of others is difficult to accept after a long life history of independent living. The positive trends among the 'young old' make the contrasts to the challenges of high age more visible, and while the 'third age' is increasingly perceived as a phase of new competences, expectations, hopes (and illusions), the 'fourth age' remains strongly associated with concepts like frailty, vulnerability, increased risks of dependency and cognitive impairments (dementia).

How far two divergent cultures of ageing and two specific policies towards a third and a fourth age are emerging is open to discussion, particularly as the boundaries between 'third age' and fourth age' vary individually and are constantly changing, giving room to permanent social and ethical discussions that have no final solutions. We will probably experience less clear-cut conflicts within an ageing society than a permanent ambivalence between an achievement-oriented culture for the 'young old' and a care-oriented culture for the 'old old'.

**S. Jay Olshansky**

(University of Chicago, School of Public Health)

Attacking Diseases by Slowing Aging

Life is the most precious of all commodities. We now live 30 years longer than we did a century ago, and our ability to manufacture healthy life has contributed to the wealth of nations and improved living standards. One unintended effect of living longer has been the rise of cancer, cardiovascular disease, Alzheimer's disease, Parkinson's disease, diabetes and non-fatal disabling conditions such as sensory impairments, osteoporosis, and osteoarthritis.

The reaction of medicine and scientific research has been to attack, one at a time, fatal and disabling diseases by identifying and modifying risk factors, or by detecting and treating them earlier. This approach to disease has so far been partially successful. Cardiovascular diseases have waned, people with many forms of cancer now live much longer than they used to, and new drugs and treatments have ameliorated many chronic diseases.

Conditions under which healthy life can be further extended are about to change. As people live longer, they are exposed to other fatal and disabling conditions that become less amenable to modification through traditional interventions. As a result, conditions of frailty and disability, including Alzheimer's disease, will soon rise precipitously.

Recent advances in aging science have yielded promising interventions that have been documented to slow aging in other species. There is reason to believe similar interventions are plausible for people. Attacking diseases by slowing aging has the advantage of delaying all fatal and disabling conditions of older people simultaneously – thus amplifying the health benefits well beyond those resulting from treatments for single diseases.

The result will be the extension of healthy life, economic benefits to individuals, and cost savings to national health care programs about to be challenged by rapid population aging.

In this presentation I will describe a new public health initiative now underway to attack diseases by slowing aging.

**Bert Heinrichs**

(University of Bonn, German Reference Centre for Ethics in the Life Sciences (DRZE))

Informed Consent in Dementia Research

In my talk I shall present the research consortium "Person and dementia" which is coordinated by Prof. D. Sturma (IWE, University of Bonn) and funded by the Federal Ministry of Education and Research under the ELSI-funding scheme. I will briefly introduce the main structure of the consortium as well as the four subprojects which it includes. Subsequently, I will focus on subproject 3 which deals with "Informed consent in dementia research". After specifying the objectives of the subproject and explicating the empirical research design, I shall present some preliminary results. Finally, I will use these results for reflecting on the concept of informed consent in general. I shall argue that the dominant view of informed consent might be one-sided in the sense that it overstates cognitive aspects. An alternative approach which takes informed consent as a communicative act might be more balanced and, as a consequence, theoretically more compelling. At the same time, such an approach could, under certain conditions, allow for informed consent by persons with MCI or similar disorders which are presently denied to consent to participating in research.

**Shelley L. Kobuck**

(University of Pittsburgh)

The Ethical Justification of Research with Advanced Stage Dementia Patients  
in the Context of Self-Determination

It is estimated that there are 5.4 million people living with Alzheimer's disease and related dementias in the United States today. The majority of people with these diseases are age 65 and older although it can have an earlier onset. As the Baby Boomers continue to age the numbers will continue to rise at a significant rate. This disease is number six in the top cause of death in the U.S. and at present it is terminal as the patient progresses through the disease process. Because there is no known cure for this disease, it has been a focus for research in attempts to find causes and treatments to slow the progress, reverse the debilitation, and prevent the disease. Although there are research trials throughout the progression of the disease, as it moves into the severe phases, there become ethical issues to justify the research. This paper will discuss the ethical justification of research with advanced stage dementia patients in the context of self-determination. The stages of the disease and the disease process will be discussed, followed by the history of the research that has been done. The benefits and the risks associated with the research will be explored as it relates to the severe phases of the disease. In outlining self-determination within the context of respect for the person and informed consent, the distinction will be made between competence and incompetence for decision-making by looking at the advance directives of living wills, treatment directives, assigning proxies, and durable powers of attorney for health care. Finally, the justification will be evaluated through the ethical theories of utilitarianism, Kantianism, rights theory, and communitarianism.

**Søren Holm**

(University of Manchester, Center for Social Ethics and Policy)

Not Growing Old – Gracefully?

Significant extensions of average life expectancy has always required societies to invent new social forms and new expectations of what it means to grow old gracefully. This paper will discuss the ethical implications of not growing old (or in reality growing old at a considerably reduced rate), and especially whether we are in a position to elucidate those ethical implications in advance of changes in social forms and expectations. It will be argued that although there is a duty to not grow old gracefully, i.e. to discharge ones moral duties in each particular segment of life, the precise contents of that duty cannot be fixed a priori, but must be discovered by the first generations who do not grow old.

**Frank Adloff**

(University of Erlangen-Nürnberg, Department of Sociology)

**Paradoxes of Planning Later Life: Anti-Ageing Practices and the Lived Body**

The process of aging is no longer being associated with a decline in liveliness and health, and the elderly have become unwilling to conform to the age-related stereotypes of the past. While their bodies do grow old, more often than not they see themselves as still active and young, their youthful 'true' self lurking beneath a 'mask of ageing'. Anti-ageing practices draw upon this cultural change in attitude. They rely on our faculty to have a body (*Körper*) and to objectify our body, to shape it and compare it with the bodies of others. The lived body (*Leib*), however, is being neglected. Anti-ageing as a discursive project of prevention reinforces the idea that the ageing body is a mask, hiding the youthful actual self. Prevention, however, is a mode of action that can never be reviewed from a future point of view (future tense II) because it is a continuous process that can never reach completion. Thus, we will never really know if our acts of prevention are going to succeed or not. Therefore, ongoing practices of prevention may result in permanent objectification of the body. This carries with it the danger of losing the feeling of security normally provided by the lived body.

**Irmela Krüger-Fürhoff**

(Center for Literary and Cultural Research in Berlin)

**'Speaking as,' 'Giving Voice to,' or 'Talking on Behalf of' People with Dementia. Ethical and Aesthetic Challenges of Narrating Alzheimer's Disease**

While the concept of the autonomous, well-informed and consenting patient has become a key model in bioethics and health care, this concept cannot be applied easily to people afflicted with progressive forms of dementia. Nevertheless most patients, relatives, and health care professionals as well as the broader public agree that even people suffering from Alzheimer's disease should be supported in giving voice to their own needs and should be granted a kind of 'assisted self-determination' for as long as possible. This holds true not only for official reports such as "Demenz und Selbstbestimmung" ("dementia and autonomy") published by the German Ethics Committee in 2012 but also for a growing number of (auto-)biographical accounts and literary works that aim to offer insights into the emotional life of Alzheimer's patients or to speak 'on behalf of' those suffering from a progressive loss of personal memory, language, and body control. My paper argues that these cultural productions play an important role in shaping both public and professional concepts of dementia by providing (resp. imagining) 'views from within.'

Analyzing German and English (auto-)biographical and fictitious texts written by patients, their family members, or writers of fiction, my paper addresses the following questions:

How are narrators who 'speak as' or 'on behalf of' Alzheimer's patients constructed as authentic or reliable? To what extent do the texts reflect on the emancipatory or manipulative aspects of 'giving voice to' the lived experience of dementia by using tape-recorded conversations with patients or by applying techniques of 'assisted writing'? Which concepts of (remaining) personal identity are offered in fiction and non-fiction books, and how do they relate to philosophical, religious or psychological notions? What are the ethical implications of presenting Alzheimer's patients as either 'individuals despite everything,' as 'returning to childhood,' or as 'mere bodies'? How do the different texts reflect the challenge of narrating the limits of narration (as based on memory and coherent language)? Can these cultural products offer specific insights and open new questions for interdisciplinary dementia research and care?



**Chiara Cerri**

(Spanish National Research Council in Madrid, Centro de Ciencias Humanas y Sociales)

The Sickness in Old Age: New Strategies of Care

Through a specific case study in this paper I propose to think about some changes that the appearance of a disease like Alzheimer involves in the representation of elderly people and in the care relationships within family.

This article is based on my doctoral research regarding the system of organizing care for the elderly people in Spain that I started in 2010 and I'm still doing. The ethnographic material used in this paper has been collected in Madrid between January and July 2012 and it has been obtained through participant observation, semi-structured interviews and informal discussion.

We are conscious that one ethnographic example is not sufficient to make generalizations, however my purpose is not to make generalizations but to show the complexity of intersubjective relationships when a disease is added at old age.

When an elderly person has a disease like Alzheimer, what does she become for everyone else? Is she an elderly person or a sick person or both? Is this person totally dependent? How do the preventive medicine and anti-aging discourse influence this situation? How is the care reorganized within family?

I will hold that the elderly and sick person's behavior is interpreted merely as result of her disease and without considering other reasons that may have led her to act a certain way. The person ceases to be understood as an individual and starts being considered only sick.

Moreover, this change in the elderly and sick person's representation leads the family to develop a new caring strategy. This new method of care is consistent with preventive medicine and anti-aging discourses and privileges the needs of the "care-givers" over the needs of the "care-receivers". It seems that the elderly and sick person has no right to make decisions for herself, which can lead to conflict among individuals involved in the care relationship.

**Perla Werner**

(University of Haifa, Faculty of Social Welfare and Health Sciences)

Competence, Like Truth, Beauty and Contact Lenses, is in the Eyes of the Beholder: Ethical Issues and Cognitive Deterioration

Due to advances in medicine and medical technology and the improvements in the social and environmental conditions, societies worldwide are confronted with the challenges of the expected dramatic growth in elderly persons. This increase will be accompanied by a concomitant growth in the number of persons with Alzheimer's disease and other dementias; an increase that has been called a public health epidemic.

In preparing for these demographic changes, researchers have discussed issues associated with the impact of cognitive deterioration and dementia at the individual, familial, societal and economic levels.

Surprisingly, the philosophical and ethical questions associated with these changes have attracted only limited attention. When examined, the main ethical issues studied were: the disclosure of the diagnosis, the efficacy and cost of symptomatic drugs especially in mild to moderate stages of dementia, and end of life issues. Competence issues, although a core ethical and philosophical question associated with cognitive deterioration, have not been extensively discussed in the literature.

The aim of this presentation is to elaborate on the topic of competence within the framework of cognitive deterioration, focusing mainly on its ethical importance and challenges.

The talk will:

- Shortly describe cognitive deterioration – with special attention to Alzheimer's disease and Mild Cognitive Impairment
- Explain the concepts of competence and capacity
- Review systematically the studies assessing competence and cognitive deterioration
- Discuss the ethical and philosophical implications of this body of research
- Develop and discuss corollaries for future research.

## Dieter Sturma

(University of Bonn, Department of Philosophy/ German Reference Center for Ethics in the Life Sciences (DRZE))

### Autonomy and Personal Identity Over Time. The Challenge of Dementia

Outline: 1. Persons, 2. The Ethical Challenge of Dementia, 3. Autonomy, 4. Personal Identity over Time, 5. The Clash between Critical and Experiential Interests, 6. A New Culture of Responsibility.

Neurodegenerative diseases, particularly those causing psychiatric disorders and dementia, pose severe challenges across a wide spectrum of issues in medicine, research, economy, politics, ethics and law. If disease risk can be demonstrated with new biomarkers decades before symptom onset, and with no preventive therapy to offer, how should that risk be communicated to the affected persons? What are the key determinants of quality of life for a person with advanced dementia—lacking understandable linguistic expression and a sense of self over time? In the field of dementia syndromes it is of vital importance which of the characteristics that may become impaired during the course of dementia-related diseases are constituents of the life of a person and which breaks of continuity that may arise from memory losses and other cognitive or affective changes affect personal identity.

A new culture of responsibility needs to be established when it comes to dealing with neurodegenerative diseases. This culture should be able to increase ethical sensitivity in everyday life, to revise our conventional notions of personal identity and to set responsibility, autonomy, paternalism, and care in a reasonable relation to each other. Objectives of the new culture of responsibility include: a) a new understanding of the life of persons over time, b) an extended responsibility for the entire life—in the first, second and third person perspective, c) the recognition of different life plans in later stages, d) the formation of a profound intergenerational and intragenerational balance, e) new guidelines for research ethics in the event of declining cognitive capabilities of probands and patients, and f) an improvement of medical research and care for the late stages of the life of persons.

## Antony Pattathu

(University of Heidelberg, Institute for Religious Studies)

### Narratives of Aging and Death: The Representation of Aging and End-Of-Life Rituals in Popular Fiction Films. The Case of Morrie Schwartz

The presentation will investigate the relation and performative formation of aging and end-of-life rituals in fiction films. These popular media representations build a crucial part of the public understanding, perception and the historical discourse on aging and death.

The main focus of the presentation will be on the case of Morrie Schwartz, a sociology Professor from Brandeis University who suffered from Amyotrophic Lateral Sclerosis (ALS) and whose process of aging and dying is represented in the movie *Tuesdays with Morrie* by Mick Jackson (1999), which is based on the best-selling novel of the same name by Mitch Albom.

Referring to his experiences as his “last great journey” and an opportunity for “growth”, Schwartz appears as a teacher for “lessons” in life. As a person who has to undergo the transition from autonomy to absolute dependency in cause of his disease at an old age, Schwartz self-reflexively deals with his own process of aging and dying and addresses the fear of aging in his “lessons”. He also designs his own end-of-life ritual, which he calls a “living funeral”. During this ritual he gathers his friends and family around him so that they may say all the things that they would like to say at his funeral, with him having the possibility to acknowledge and enjoy it.

Contrasting this case with fiction films that provide similar examples the movie will be analyzed in terms of the different layers, its narrative structure, the “lessons” and the surrounding media discourse to the film. The normative structures and values that are offered by these examples are mediating a harmonizing view on aging and dying and also resonate with the thanatological discourse on the concept of a “good death”. The presentation will give a critical account how these values subvert or reaffirm the rights, agencies and ethics of aging and dying to use them as a diagnostic indicator and incentive to discuss the changing images of aging and death.

**Claudia Bozzaro**

(University of Freiburg, Institute of Ethics and the History of Medicine)

Aging between Autonomy and Vulnerability

Since aging is characterised by increasing loss of autonomy and dependency, this life stage can be considered one of vulnerability *par excellence*.

Because of this vulnerability, providing adequate assistance to the elderly represents an obvious challenge for medical doctors, in particular geriatricians and gerontologists. A new kind of medical approach towards aging has developed in the last twenty years: anti-aging-medicine. In contrast to geriatrics, anti-aging-medicine focuses not only on methods that attempt to prevent age-related vulnerability, but also on strategies that aim to combat the aging process itself.

These two medical approaches are informed by distinct conceptions of what constitutes “good aging,” as well as different ways of understanding vulnerability and autonomy in relation to aging.

In this presentation, I begin by describing the vulnerability of aging. To do so, I rely on phenomenological studies about bodily change and elderly people’s perception of time, and on psychological studies about shifts in their personal and social lifestyle.

I then analyse the two conceptions of “good aging” that are prevalent in anti-aging and geriatric medicine and show that these can be ascribed to two western philosophical- cultural traditions.

I then move on to analysing the anthropological presuppositions that inform these two conceptions. Finally, I present some conclusions about the importance of the concept of vulnerability for medicine and about the highly charged relationship between the concept of vulnerability and the concept of autonomy.

**Silke Schicktanz**

(University of Göttingen, Department for Medical Ethics and History of Medicine)

We Are Many! The Role of Alzheimer Advocacy Groups for Public Bioethics

Dementia is one of the ageing-correlated diseases that has gained extensive public attention in recent years. Related bioethical issues are manifold: diagnosis and stigmatization, priority setting in therapy, research and care, and in research participation. In my presentation, I want to illuminate the role of the voices of affected persons, mainly advocates, in public bioethics. As influential patient advocates *The Alzheimer’s Association* can be named in the US context and the *Deutsche Alzheimer Gesellschaft (German Association of Alzheimer’s)* in Germany. I will compare their positioning towards the ethically challenging topic of research participation of mentally impaired patients with academic bioethics. From a theoretical point of view, research participation of cognitively impaired patients is ethically very problematic if it is research with mainly third-party benefit. In many fields of research on dementia this, however, is the case, e.g. when developing new diagnostic or predictive tools or in early phases of pharmaceutical research. Hence, I first want to illustrate the relevance and context-sensitive policy of patient advocates for deliberating such ethical dilemmas, and second, raise the ethical-political question of how to adequately involve the perspective of those affected.

## Andreas Kruse

(University of Heidelberg, Institute of Gerontology)

Vulnerability and Developmental Potentials in Border Situations:

To a Comprehensive Understanding of Very Old Age from an Individual,  
Cultural and Political

The growing number of older people does not constitute a burden on our society today, but rather a potential benefit. To see this, it is necessary to assume a potential perspective and investigate how much potential ("development opportunities") people can realise in old age when they have been given training which supports development during the course of their lives. These development opportunities form the basis for integrity and generativity, whereby the former is interpreted in terms of the acceptance of one's own life and a positive attitude to life (in respect of the person's own ability to come to terms with their limits), the latter in the sense of shared responsibility for subsequent generations. A co-responsible life is interpreted by many older people as an important element in their quality of life and sense of fulfilment. For this reason, both at the local community level, but also in companies, more opportunities for exchange and collaboration between generations need to be created. The potential discourse must not deny the vulnerability of people in old age, especially in very old age. Rather, it is necessary for our society to adjust to this vulnerability by creating a "vulnerability-sensitive" environment, transport, accommodation and living space design, as well as by providing adequate utility and service structures, and promoting self-reliance and co-responsible living, even in more challenging situations. At the same time, social and cultural participation is influenced by the human images of increased vulnerability which recognise the limitations and mortality of people who, due to chronic disease and the need for care, are without the mental emotional development potential and motivation to participate, or who even overlook the end of life itself

## Mark Schweda

(University of Göttingen, Department for Medical Ethics and History of  
Medicine)

When I'm 640. Prolongevity and the Ethics of the Human Life Course

Anti-aging medicine aims to slow down, stop or reverse the aging process, and to radically extend human life. This project has provoked controversial bioethical debates, e.g., about feasibility, chances and risks, goals of medicine, and social consequences. On a more fundamental level, however, it also challenges some of our long-standing and most common beliefs concerning the life span and life course as such, thus shedding light on the ethical significance of the temporal dimension and structure of human existence.

Against this background, I will plead for broadening the theoretical perspective: The discussion of the pros and cons of anti-aging has to be framed in a more profound approach to human temporality. In lack of elaborate ethical conceptions in this field, I will start from the sociological *life course approach*. According to this approach, an individual's life has to be regarded as a sequence of phases and thresholds structured by socio-cultural norms and tied to specific statuses and roles, options and expectations. Individual conceptions of this schematic course function as an "inner clock" normatively framing personal choices and life decisions.

I will argue that this perspective should be made productive for the bioethical debate. To this purpose, I will first sketch main positions on anti-aging and their underlying assumptions, then delineate the basic elements of the life course approach and their ethical implications. Two categories appear particularly relevant: In a *deontological perspective*, the idea of *age norms*, social standards of age-appropriate behavior; in a *teleological perspective*, the concept of *life plans* comprising biographical expectations and developmental tasks. I will exemplify the potentials of these categories in the empirical analysis of group discussions with lay persons on radical life extension. Concluding, I will argue that the life course perspective not only allows *critically* uncovering hidden biases in the debate on anti-aging, but also provides a promising basis for developing a more profound understanding of the ethical significance of human temporality in general.

**Robin L. Pierce**

(University of Delft, Department of Biotechnology)

Synthetic Biology in Molecular Medicine: Forging a New Relationship between Aging and Disease?

The possible use of synthetic biology in developing the capability to detect and intervene on the basis of biochemical markers indicative of pathology will signal a shift in healthcare. In essence, as a theragnostic technology, synthetic biology could operate as an internal “biophysician”, performing both diagnostic and therapeutic functions. However, this development comes with multiple complexities, including implications for the concept of disease and illness. If an internal mechanism effects cure upon manifestation of emerging pathology, the “disease” never actually materializes. Yet since disease and malfunction are also associated with aging, then in principle, this technology could intervene in the natural aging process.

This will surely signal a major development in the promotion and maintenance of health and well-being, but it also has the potential to fundamentally alter the concept of aging as well as therapy. In treating disease, theragnostics, in some instances, will also “treat” aging. In addition to the implications of an amplified demographic shift, there are multiple implications for deeper societal values. Will aging become stigmatized in new ways such that aging becomes a marker of low socio-economic status, poor health care, or rural versus urban residence? Resource allocation issues that currently hover over health care policies for eldercare can be expected to appear in this context as well, i.e. will we be counting expected gains in QALYs in deciding allocation as between e.g. a young man with prostate cancer whose recurrence can be prevented versus an 80 year old wanting to ward off the plaques and tangles associated with Alzheimer’s. Will we be required to re-visit “Fair Innings” policy approaches? This paper explores the implications of theragnostics for aging and the treatment of age-related diseases from a policy perspective, beginning with an attempt to clarify the underlying conflation between aging and disease occasioned by this technology.

**Noelia Bueno Gomez**

(University of Oviedo, Institute of Ethnology)

Autonomy versus Dependency in the Old Age: A Reconsideration from a Narrative Conception of Personal Identity

The risk of dependency increases in old age. This dependency can be especially painful if it parallels (as usually happens) with a lack of autonomy, what can be perceived as a rupture in the personal story, especially when the person has lived an active social and political life in which he/she was responsible of any tasks and has made its own decisions. Thus when the person has already a story that he/she can tell and in which he/she can recognize a style of living, a personal identity.

There are certain systems of power-relationships whose intrinsic logic tends to reduce or remove the personal autonomy of one of its members. This happens with the expert/non-expert relation when it operates over the non-expert’s body. Healthcare assistance and care provided for treating illness or disability usually functions with the logic of techno-science: after a diagnostic that classifies the illness and/or the degree of dependency, it starts the correspondent technological intervention in the patient. This logic is utilitarian: certain means are used to achieve an end, to restore health and, frequently in old age, palliate the symptoms of a disease. The gap among healthcare assistants and the dependent old person comes from the fact that they know and apply in his/her body techniques that he/she does not know, understand, can control or even accepts. This situation of special vulnerability needs a special protection, much more than an “informed consent” that is not enough to restore certain degree of autonomy.

My proposal looks to explain why certain degree of autonomy is compatible with dependency and how this particular power-relationship can be modified for protecting the autonomy.

I will use a philosophical methodology, taking into account relevant information and tools from binding fields on this topic, like the Katz index of independence in ADL.

**Helena Hermann, Manuel Trachsel and Nikola Biller-Andorno**  
(University of Zurich, Institute of Biomedical Ethics)

The Dual Process Model of Information Processing in Medical Decision-Making Capacity

Decision-making capacity (DMC) is a prerequisite for informed consent that serves the patient's right to self-determination. Diagnosed as being incapable has important implications for patients' involvement in treatment decisions. From an ethical perspective, DMC judgments reflect the tension between the moral duty to respect the autonomy of those who are able to make their own decisions and to provide protection for incompetent patients. The issue of whether or not an individual has the DMC for treatment choices is particularly relevant with regard to patients belonging to vulnerable groups like for example the cognitively impaired elderly. In order to define and assess DMC, the following four standards have been proposed (Appelbaum & Grisso, 1995): (1) evidencing a choice, (2) understanding, and (3) appreciation of disclosed information, and (4) reasoning. These criteria strongly emphasize cognitive abilities and seem to imply that a competent decision is exclusively based on rational deliberation. However, psychological theory and empirical research on decision processes indicate that decision-making is based on two modes of information processing: an intuitive/affective mode and a reflective/deliberative one (e.g. Evans & Frankish). In addition, there are considerable age differences in the relative importance of these two modes with a shift to intuitive/affective processing in older ages (Peters et al., 2011). Thus, older adults in comparison to younger adults show different kinds of information processing and preference construction due to motivational as well as cognitive changes. Such empirical findings challenge the current purely cognitive notion of DMC according to which older adults may be unjustifiably deemed incapable. Moreover, the appropriateness of the prevailing definition of a competent decision as one only based on conscious and deliberative processing may be questioned. The presentation aims to explicate the above-mentioned statements and to discuss alternative ways of conceptualizing competent decisions.

**Larissa Pfaller**  
(University of Erlangen-Nürnberg, Department of Sociology)

From Users to Adherents – Anti-Aging as a Way of Life: Qualitative Interviews and Biographical Perspectives

At least since the founding of the A4M (American Academy of Anti-Aging Medicine) in 1993, anti-aging medicine has formed a discrete discipline, implementing scientific findings for purposes of prevention, early diagnosis, reversal or treatment of age-related changes and loss of body functions. In recent years, anti-aging has also been established in Europe, as the institutionalization of anti-aging medicine in Germany shows in an exemplary way.

Despite the growing significance of anti-aging, its impact on the *users'* everyday life has hitherto been under-explored. This presentation focusses on users of anti-aging products and services in Germany and is based on 15 narrative interviews conducted in the context of the research project "Biomedical life plans for aging".

The interviews show the profound impact of anti-aging on the individuals' biographies: Although users cannot observe the effectiveness of their practices, they are invested with biographical meaning. Therefore, it is supposed that the persistence and attractiveness of anti-aging practices goes far beyond their scientific persuasiveness. Within the reconstruction of the significance of anti-aging for the interviewees' biographies, the *symbolic and emotional potential* of the practices are to be examined: Anti-aging turns out to be an ideal staging ground for presenting oneself as a rational actor and a self-caring subject. Anti-aging can thus be described as a form of *lifestyle* that is committed to an ideal of scientific rationality and the moral values of individuality and responsibility.

**Tobias Eichinger**

(University of Freiburg, Institute of Ethics and the History of Medicine)

**Prevention of What? Ethical Aspects of the Medicalisation of Aging**

Medicalisation has many faces. From the very beginning of life – childbirths in hospitals – to the end of it – dying under the doctor’s eyes – ranges the influence of medical thinking and acting. Medicalisation is also normative ambiguous. Whereas the defining and handling of a problem in medical terms and treatments could mean a great help and relief to the person(s) concerned, it also could lead to problematic consequences on an individual, social and conceptual level.

That complex ethical diagnosis also regards the case of medicalised aging. On the one hand, there has been developed and introduced a lot of helpful medical innovations for elderly people alleviating the burdens of old age and keeping their activity and capacity to lead a self-determined and fulfilled life as long as possible, a development which could be interpreted as appropriate answer in technoscientific and consumer societies to the ongoing rise of life expectancy.

On the other hand the increasing medical treatments and clinical age research change (more or less implicit) the common understanding of what it means to grow old – and what every single person has to do in preparation of that later phase of life. Due to its process of medicalisation, aging becomes more and more a project, a project for whose course and success the individual is fully responsible. Moreover the perception of aging strongly emphasises somatic and thereby deficient bodily aspects. A quite radical but consistent step further on the path of medicalisation declares aging itself as disease that medicine has to cure.

**Clara Berridge**

(University of Berkeley, UC Berkeley Designated Emphasis Program in Women, Gender & Sexuality)

**Subjecting One’s Self to Monitoring:****Decision Making about the Option to Use Remote Monitoring Technologies in a Low-Income Independent Living Residence**

A significant innovation in home care technology is the shift from actively triggered social alarms to passive remote monitoring. This transition to sensors and other devices that enable position and vital sign tracking is an important one because it reconfigures the person who is under surveillance, thereby reconfiguring the socio-technical practice. These technologies have the potential to reorganize roles and responsibilities for providing care because the practices themselves are reshaped with new devices serving to mediate care. Remote monitoring (RM) has been proposed as a way to revolutionize home healthcare by enabling earlier detection and prevention of health events, enhancing the independence of vulnerable older adults and delaying health-related relocation; however, the processes and social implications of the emerging RM practice are poorly understood. Findings from extant studies illustrate what Pascale Lehoux calls “the dual performative potential of health technologies.” The dual performative potential of remote monitoring, or the coexistence of positive and negative effects, which may act to reinforce/weaken identity, decrease/increase or facilitate/impede autonomy, power, uncertainty, and risk, further complicates the diverse landscape of meanings associated with *independence* and multi-dimensional concepts like *obtrusiveness* and *privacy*. At this early stage of RM implementation, we know little about how these opportunities and concerns play out during real-life decision making about RM technology use. This presentation draws on findings from participant observation of meetings in which RM sensor technology is offered to older adult residents of an inner-city, low-income Independent Living Residence in the U.S., along with interviews with them and their professional caregivers and family members over a six-month period. The observed decision making will be the basis for a discussion of how these residents of subsidized senior housing reflect upon and negotiate their fears, hopes and the ethical aspects of remote monitoring.

**Michel Coors**

(University of Hannover, Center for Health Ethics)

**Imagine a Life ... The Impact of Imagination on Ethical Decisions**

Questions: Planning later life requires imagining the situation of becoming old. Communicating with old people suffering from dementia requires imagining how it is to live with dementia. Dealing with the results of predictive diagnostics regarding the potential risk of dementia also requires the capacity to imagine later life. Obviously imagination is a capacity that is essential to ethical deliberation, especially in an aging society. This paper aims at clarifying how imagination is involved in ethical reflections on later life.

Method: This is achieved by an analysis of the concept of imagination in different philosophical contexts: The ethical theories of Hannah Arendt and of Iris Murdoch both refer to the concept of imagination. Both refer to Kant's Critique of Judgment and its theory of aesthetic judgment. The paper will discuss the concept of imagination in these three authors: How is the aesthetic concept of imagination transformed into an ethical concept? What impact does it have on the processes of ethical decision making?

Results: In Kant's theory of aesthetic judgment, imagination is related to reason and common sense. Therefore aesthetic judgments are always judgments within a community. Arendt picks up these considerations and transforms the theory of aesthetic judgment into a theory of political and ethical judgment. Murdoch's ethical theory focuses on the productivity of imagination in ethics. All three authors demonstrate that ethical judgment relies on the capacity of imagination and that the limits of imagination are set by the common sense within a social community. Thus the more an ethical decision in medicine relies on imagination, the more do social factors gain influence on the individual's decision.

**Ralf J. Jox**

(University of Munich, Institute for Ethics, History and Theory of Medicine)

**Advance Refusal of Treatment and Organ Donor Cards: An Ill-Matched Couple?**

In Europe, more and more elderly citizens write directives documenting advance refusals of medical treatment for the end of life. The most recent polls suggest that every second German citizen over the age of 65 years has already done that. At the same time, citizens are publicly, legally and medically nudged to issue organ donor cards for post-mortem donation, and even the elderly are increasingly considered potential organ donors. Many advance directives contain the decision about being an organ donor or not. Yet, the relation between these two types of anticipatory statements is far from trivial. While advance directives primarily intend to enable a peaceful, natural dying outside of a high-technology medical care setting, post-mortem organ donation requires exactly this: high-tech intensive care to guarantee full organ functioning. In this presentation, I will analyse this dilemma, outline the conflicting clinical scenarios and the underlying ethical problems. I will consider the pertinent literature and suggest ways of addressing the problem in order to facilitate decision making.



**Claire Rommelaere**

(University of Namur, Faculty of Sciences)

Mental Disorders and Advance Directives about Healthcare. Responses of Belgian Law to a Future Incapacity to Make (One's Own) Decision

“Planning later life” raises the question, among others, of an eventual future mental incapacity to make decisions for oneself, including healthcare decisions. Therefore, the will of planning later life may also be expressed in “advance directives” which are to take effect in case of mental incapacity. Mental health law may provide for such advance directives. Those can be divided in three groups: advance directives about healthcare, about death (through refusal of healthcare or advance statement of euthanasia) or, less directly, about representation. In the latter, patients do not decide about healthcare or euthanasia but choose someone who will make healthcare decisions on their behalf in case of (mental) incapacity.

In the context of the Conference, I wish to expose what Belgian law provides in that field, in comparison with other countries such as Canada and Netherlands, to try to determine if our legal possibilities of “advance directives” are the best way to ensure respect of the autonomy of the patient with a mental disorder and to what extent those directives limit the healthcare professional’s own autonomy.

The proposed analysis is a legal one, so that it is mainly based on legal texts, enlightened by legal literature and judicial decisions. Belgian law is the starting point of the research but international law or recommendations and elements of comparative law will also be taken into account, as well as principles of bioethics such as “autonomy”, “beneficence” and “nonmaleficence” (principles developed by T. BEAUCHAMP and J. CHILDRESS in Principles of biomedical ethics, 5th ed. New York City, NY: Oxford University Press; 2001).

**Julia Inthorn**

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Age as Normative Argument? Lay Persons Perspectives on Medical Decisions in an Intercultural Comparison between Germany and Israel

Background and Aim: Characteristics of a person such as age are usually not considered a valid argument within debates in medical ethics due to the problem of discrimination. In everyday life when people talk about life plans or reason for their decisions references to a persons age often are often made. The paper assesses how lay persons from different cultural backgrounds use age as an argument within normative reasoning and discusses these arguments from an ethical perspective.

Method: In an intercultural comparison between Israel and Germany we assessed the perspective of lay persons on end of life decisions and the use of genetic testing for individual life plans through focus groups. The main focus of the research project lies on concepts of shared responsibility in medical decision making and normative arguments of lay persons.

Results: Lay persons – in Germany as well as in Israel – refer to age as an argument in various ways and for this they use different concepts of age such as being a member of a certain generation, ideas of a life fully lived or average life expectancy. Within their reasoning lay persons link normative ideas of a good life to ideas of a good death.

The analysis of lay arguments using age shows the importance of images of a good life for end of life decisions as well as the plurality of them and differences between cultures. Lays use age as an argument as a metaphor through which different ideas of a good life can be transformend into more general arguments concerning end of life decisions.

**Kai Brauer**

(University of Kärnten, The School of Health and Social Science)

Final Decisions for the Final Crisis. Hopes and Hypes of the Advance Directive in Germany

After a legal provision on advance health care directives (AHCDs) in Germany, it has become possible for Germans to make legally binding decisions regarding one's end of life before actually being affected by the final crisis such a decision is normally linked to. It has often been remarked that this constitutes a paradox: The way such a crisis plays out, as well as its concrete influence on oneself, cannot be grasped without having experienced it in the flesh. How then is one to make such an existential decision in advance? Focus group discussions of laymen, conducted during the research project "Biomedical Life Plans for Aging – Values Between Individual Ethical Reflection and Social Standardization", have shown that this uncomfortable question is by all means being acknowledged. But mere awareness of a paradox does not equal to its solvability: Nobody will ever be able to plan "correctly" for a medical emergency that ultimately revolves around a conflict between survival instinct and the decision to end one's life. Nevertheless, the preparation of an AHCD to deal with complex existential situations at the immediate end of life has been deemed necessary by a majority of participants. This preparation for the future allows for a twofold effect in the present:

1. Hope: An AHCD allows for a feeling of security not unlike an insurance policy in that it is supposed to protect from "additional" or needless pain and agony at the end of life. The underlying idea here is that modern medicine does not permit the experience of an "honorable" or quick death. Unavoidable remaining insecurities and paradoxes (such as dying "too" quickly) are typical for formation processes that elude completion. Here, the act of preparing an AHCD functions as an attempt in the search for more self-determination and decision-making autonomy, especially regarding a possible phase in life that prevents communicating one's decisions and desires. AHCDs are thus an expression of the fundamental social process of individualization and institutionalization of personal biographies.
2. Hype: AHCDs permit the health care system as a whole and intensive care physicians in particular the redirection of responsibility for unpopular, high-impact decisions back towards the patient. A legal provision regarding AHCDs was therefore widely called for in this field. Furthermore, such a fundamental decision was in high demand by the legal system itself. Not

only did this result in reinforcing the rights of patients at their end of life, it also furthered critical reflexion regarding rights of patients in general.

This presentation will discuss whether or not actors are able to conceive of AHCDs as instrumental for the closure of their final crisis – therefore finalizing the process of subject formation, and thus fulfilling the quite understandable hopes of patients (as well as professionals working in palliative and hospice care). An alternative interpretation would suggest that AHCDs do not help in resolving their fear of pain while dying at all. They are rather seen as resultant of a desperate final decision that expresses a denial of the ambivalences of dying, and analogously, of living. According to Erikson, this denial would provide a basis for fixations that express disgust in oneself and others through a subconscious fear of death. AHCDs, then, would do nothing to resolve this fear, but rather make it manifest in the first place.