

# RIASE

REVISTA IBERO-AMERICANA DE SAÚDE E ENVELHECIMENTO  
REVISTA IBERO-AMERICANA DE SALUD Y ENVEJECIMIENTO

**BIOETHICAL PERSPECTIVES FOR AGEING.  
THE DOCUMENTS PRODUCED  
BY THE ETHICS COUNCILS**

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## ABSTRACT

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Aging attracted keen interest in research, health, education as well as cross-sectors approaches. We researched what has been produced by the National Bioethics/Ethics Councils in the form of opinions or other documents, relating to aging and elderly people. In the websites of the 28 EU councils and 12 other countries, we identified 4 documents relating to aging and 8 opinions, which we analyse. The Councils have proposed to draw the attention and reflection of public opinion to the elderly condition; all agree that the age has its own traits and that matters revert to a “culture of old age”, respect and promotion of a positive aging. Enhance the diversity of modes of aging and the importance of preparing all, promoting literacy for aging, creating social and legal protective elements (Elderly Statute, Observatory of the Elderly Conditions). From the analysis, a set of principles and bioethical elements: [1] respect for human dignity, regardless of the stage of life; [2] recognition of the person’s situation uniqueness to aging; [3] freedom of one’s own decision, which is materialized in respect for autonomy; [4] recognition of the vulnerabilities of the elderly, [5] ethical commitment and social responsibility in monitoring the elderly, [6] non-discrimination by age and [7] the guidance to the conditions of the integral good and quality of life. Aging is an existential step for which we can prepare, on the assumption that human life in its longevity, interweaves those who are older and those younger, on the crucial issue of human existence.

**Key-words:** aging, bioethics, opinions bioethics councils

## FRAMEWORK

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Aging is raising an enormous interest in research, health and education, as in transversal and intersectoral approaches. Within the reasons, you either name the demographic changes of the population with the increase of the average life expectancy, the support in lines and projects of investigation or the focus of plans and national health programs. So, we consider helpful and relevant inquire about the way aging appears in the bioethics reflection.

Aging happens from life time and people are conscious of the impact of an elderly population and dependent elders as well as their need of the health services – maybe because of that, in the last years, some bioethics reflection have focused on the distribution of the resources in health. Another perspective has focused on the matters of the end of life and the lost of personal autonomy related with aging. But these are not (or they don’t look like they are) the only relevant approaches concerning aging. Since it is a biological process, it

won't stop having social and cultural relevance, nor will it stop from being a human and existential framework. Eventually, the matter progresses from aging to the way as aging is seen and lived. That is why, we should go beyond resource distribution and distributive justice, so that aging can be seen as a potential source of ethic questions about the meaning of life and living together with the finiteness.

On this trail of thought, we understand the importance of researching what has been produced by the Ethic National Councils, in a way of opinions and other documents. Truth be told, this concern surfaced when the discussion, in the National Council of Ethic for the Life Sciences in Portugal, of the Opinion n° 80/2014, "Opinion on the vulnerability of elderly people, especially the ones living in institutions", which originated from the Council's own initiative; and we questioned ourselves if there would be other Council's pronouncing themselves.

For this research, we started from the following questions: what are the opinions of the Ethic Councils from the European Union regarding aging and elderly people? which principles are used for the bioethics anchorage on the approach concerning aging? and what bioethics approach do we find in aging?

#### *Data collection/Methods*

The reality of the European Union of the 28, there are Ethic Councils in every country, named as Ethic Councils for the Life Sciences, Bioethics Councils, Medical Ethic Councils or related titrations.

In a first step we proceeded to the identification of all the Councils and consulted the websites as listed on the following chart.

We performed the consultation of all the websites, when possible in their original language (in our comprehension) and in the English translation, happening that on this case, the availability of texts varied lot depending on the country.

We conducted the search with three key-words in three idioms: "pessoas idosas - elderly - personne âgée", "envelhecimento - aging - vieillissement", "envelhecer - age - âge" following with the association of "auto-determinação - self-determination - autodétermination" and "vulnerabilidade - vulnerability - vulnérabilité".

The opinions resulting of the researches and other data present in the websites that we thought might be related were read. We placed aside the analyses of the opinions concerning the end of life<sup>i</sup>, clinical investigation<sup>ii</sup>, people incapable of consenting<sup>iii</sup>, neurosciences and neuro-improvements<sup>iv</sup>, robotics and technology analyzed in a general perspective<sup>v</sup>,

Chart 1 - Ethic Councils identification, in EU 28

EU 28	Council/Committee	Year	Site
Germany	Deutscher Ethikrat - German Ethics Council	2007	<a href="http://www.ethikrat.org/">http://www.ethikrat.org/</a>
Austria	Austrian Bioethics Commission	2007	<a href="http://www.bundeskazleramt.at/site/4070/default.aspx">http://www.bundeskazleramt.at/site/4070/default.aspx</a>
Belgium	Comité consultatif de Bioéthique de Belgique - Belgian Advisory Committee on Bioethics	1993	<a href="http://www.ccne-ethique.fr/en">http://www.ccne-ethique.fr/en</a>
Bulgaria	Bulgarian Center for Bioethics	2004	<a href="http://www.bio-ethics.net/en">http://www.bio-ethics.net/en</a>
Cyprus	Cyprus National Bioethics Committee	2001	<a href="http://www.bioethics.gov.cy/moh/cnbc/cnbc.nsf/index_en/index_en?OpenDocument">http://www.bioethics.gov.cy/moh/cnbc/cnbc.nsf/index_en/index_en?OpenDocument</a>
Croatia	Committee for Medical Ethics and Deontology	1996	Sem site. Separou-se da Croatian Medical Association
Denmark	Danish Council of Ethics	1988	<a href="http://www.etiskraad.dk/da-DK.aspx?sc_lang=en">http://www.etiskraad.dk/da-DK.aspx?sc_lang=en</a>
Slovakia	Ethics Committee of the Ministry of health of the Slovak Republic	2004	Sem site. Ministério Saúde. 8 regional ethics committees
Slovenia	National Medical Ethics Committee, NMEC	1998	<a href="http://www.kme-nmec.si/">http://www.kme-nmec.si/</a>
Spain	Comité de Bioética de España - Spanish Bioethics Committee	2007	<a href="http://www.comitedebioetica.es/">http://www.comitedebioetica.es/</a>
Estonia	Estonian Council of Bioethics	1998	<a href="http://www.eetikakeskus.ut.ee/en/estonian-council-bioethics-0">http://www.eetikakeskus.ut.ee/en/estonian-council-bioethics-0</a>
Finland	National Advisory Board on Health Care and Ethics	1998	<a href="http://www.etene.fi/en">http://www.etene.fi/en</a>
France	Comité consultatif national d'éthique pour les sciences de la vie et de la santé	1983	<a href="http://www.ccne-ethique.fr">http://www.ccne-ethique.fr</a>
Greece	Hellenic National Bioethics Commission	1999	<a href="http://www.bioethics.gr/">http://www.bioethics.gr/</a>
Holland	The Netherlands Centre for Ethics and Health (CEG)	2003	<a href="http://www.ceg.nl/en">http://www.ceg.nl/en</a>
Hungary	Scientific and Research Ethics Committee of the Medical Research Council	2002	Sem site. Integrado no Ministério Saúde
Ireland	Irish Council for Bioethics [extinto em 2010]	2002-2010	<a href="http://www.bioethics.ie/">http://www.bioethics.ie/</a> <a href="http://bioethics.academy.ac.il/english/Links/Ireland.html">http://bioethics.academy.ac.il/english/Links/Ireland.html</a>
Iceland	National Bioethics Committee of Iceland	1997	<a href="http://www.vsn.is/en/content/home">http://www.vsn.is/en/content/home</a>
Italy	Comitato Nazionale per la Bioetica (CNB)		
Lithuania	National Bioethics Committee	1990	<a href="http://www.governo.lt/bioetica/">http://www.governo.lt/bioetica/</a>
Luxembourg	Lithuanian Bioethics Committee	1995	<a href="http://bioetika.sam.lt/index.php?-1876243809">http://bioetika.sam.lt/index.php?-1876243809</a>
Malta	Commission Consultative Nationale d'Ethique pour les sciences de la Vie et de la Santé.	1988	<a href="http://www.cne.public.lu/">http://www.cne.public.lu/</a>
Poland	Bioethics Consultative Committee	2000	<a href="https://ehealth.gov.pl/healthportal/others/regulatory_councils/bioethics_committee/bioethics_committee_home_page.aspx">https://ehealth.gov.pl/healthportal/others/regulatory_councils/bioethics_committee/bioethics_committee_home_page.aspx</a>
Portugal	Bioethics Appeal Commission (Ministry of Health)	1997	<a href="http://www.mz.gov.pl/rozwoj-i-inwestycje/nauka/komisje-bioetyczne/odwolawcza-komisja-bioetyczna">http://www.mz.gov.pl/rozwoj-i-inwestycje/nauka/komisje-bioetyczne/odwolawcza-komisja-bioetyczna</a>
United Kingdom	Conselho Nacional de Ética para as Ciências da Vida (CNECV)	1990	<a href="http://www.cnevcv.pt/">http://www.cnevcv.pt/</a>
Kingdom	Nuffield Council on Bioethics	1991	<a href="http://www.nuffieldbioethics.org/">http://www.nuffieldbioethics.org/</a>
Republic Czech	Central Ethics Committee of the Ministry of Health of the Czech Republic	2011	Sem site. Research, development and innovation council <a href="http://www.vyzkum.cz/">http://www.vyzkum.cz/</a>
Romania	Comité national roumain de bioéthique	?	<a href="http://www.cnr-unesco.ro/ro/index.php">http://www.cnr-unesco.ro/ro/index.php</a>
Sweden	Swedish National Council on Medical Ethics (SMER)	2001	<a href="http://www.smer.se/en/">http://www.smer.se/en/</a>

donation and transplantation<sup>vi</sup> of organs – after read and understood it did not include references concerning aging.

On the website of the Swedish Council there was a disclosure of a new project about the ethic aspects on robots and vigilance in the health of the elder, having the Council debated if it is ethical acceptable to allow the so called co-payments in the public health area when it is about the complementary health services and products that aren't considered by the public financing (it was advised that the report would be published in October 2014 but such didn't happen until December).

We didn't identify the opinions concerning the thematic area of aging in the large majority of the Councils – same Councils with production on matters regarding social and age groups, like Finland's<sup>vii</sup>, or with production within diverse and comprehensive areas, such as the Hellenic Council<sup>viii</sup>, or one of the oldest, like the French Council<sup>ix</sup>, that don't have a specific opinion regarding aging or elderly people. The Luxembourg Council dedicated a clause towards the protection of youth<sup>x</sup>, but we did not find references concerning aging. The websites of the Councils of Croatia, Estonian, Latvian and Slovakia were not found.

Following this research we had a sample of two specific opinions about aging from the Portuguese and Italian Councils. We equally collected opinions of the Councils of Germany, Belgium, Netherlands, Italy, United Kingdom and Sweden with other themes but that mentioned, at least one reference, to aging.

We decided to expand to other countries, also for an eventual compared approach. We proceeded to the identification and consultation of the website's documents, according to chart 2, this time leaving countries of European Union out.

Chart 2 - Identification of other Councils

Country	Council/Committee	Site
South Africa	National Health Research Ethics Council (NHREC)	<a href="http://www.nhrec.org.za/">http://www.nhrec.org.za/</a>
Algeria	Conseil National de l'Éthique des Sciences de la Santé	<a href="http://www.sante.dz/">http://www.sante.dz/</a>
Australia	Australian Health Ethics Committee (AHEC)	<a href="http://www.nhmrc.gov.au/about/committees-nhmrc/australian-health-ethics-committee-ahec">http://www.nhmrc.gov.au/about/committees-nhmrc/australian-health-ethics-committee-ahec</a>
Brazil	Comissão Nacional de Ética em Pesquisa (CONEP) integra Conselho Nacional de Saúde	<a href="http://conselho.saude.gov.br/Web_comissoes/conep/index.html">http://conselho.saude.gov.br/Web_comissoes/conep/index.html</a>
Canada - Québec	Commission de l'éthique de la science et de la technologie	<a href="http://www.ethique.gouv.qc.ca/fr/">http://www.ethique.gouv.qc.ca/fr/</a>
USA	Presidential Commission for the Study of Bioethical Issues (Bioethics Commission)	<a href="http://bioethics.gov/about">http://bioethics.gov/about</a>
Philippines	Philippine Health Research Ethics Board (PHREB)	<a href="http://ethics.healthresearch.ph/">http://ethics.healthresearch.ph/</a>
Singapore	Bioethics Advisory Committee	<a href="http://www.bioethics-singapore.org/index/publications/reports.html">http://www.bioethics-singapore.org/index/publications/reports.html</a>
Nordic countries	Nordic Committee on Bioethics	<a href="http://ncbio.org/english/">http://ncbio.org/english/</a>
Japan	Bioethics Council Safety Committee for Science and Technology	<a href="http://www.lifescience.mext.go.jp/bioethics/">http://www.lifescience.mext.go.jp/bioethics/</a>
Switzerland	Commission nationale d'éthique pour la médecine humaine, CNE - Swiss National Advisory Commission on Biomedical Ethics	<a href="http://www.nek-cne.ch/en/index.html">http://www.nek-cne.ch/en/index.html</a>
Tunisia	Comité National d'Éthique Médicale	<a href="http://www.comiteethique.rns.tn/ethique/ethique.html">http://www.comiteethique.rns.tn/ethique/ethique.html</a>

The texts of the Japanese council are only available in English when regarding the genetic investigation, biobanks and guidelines connected to the research of human genome. Once again, we did not include opinions about the anticipated directives<sup>xi</sup>, health costs<sup>xii</sup> or others that did not mention, in the text, aging. In international terms, there are clearly themes in common, such as the medical assisted procreation, new technologies, research in human beings, interruption of pregnancy, transplants and donations, VIH, amongst others – that are found in either the United States or Portugal opinions, as in the Tunisian Council<sup>xiii</sup>. The President’s Bioethics Commission of the United States has extensive studies in areas related to age<sup>xiv</sup> or social groups and one Report *Taking Care: ethical care giving in our aging society*<sup>xv</sup>, which we included.

Resulting of this research we collected a sample of **two documents** specific about aging of the United States and Tunisia, and **one Opinion** from Québec with other theme that includes aging.

Whereas scarce production in this area, we decide investigate whether there would be other documents with bioethical content emanating from international organizations, ethics or bioethics committees, according to the chart 3.

Chart 3 - Identification of international organizations

Organizations	Council/Committee	Site
UNESCO	International Bioethics Committee (IBC)	<a href="http://www.unesco.org/new/en/social-and-human-sciences/themes/bioethics/">http://www.unesco.org/new/en/social-and-human-sciences/themes/bioethics/</a>
	Intergovernmental Bioethics Committee	<a href="http://portal.unesco.org/shs/en/ev.php@URL_ID=1878&amp;URL_DO=DO_TOPIC&amp;URL_SECTION=201.html">http://portal.unesco.org/shs/en/ev.php@URL_ID=1878&amp;URL_DO=DO_TOPIC&amp;URL_SECTION=201.html</a>
World Health Organization - WHO		<a href="http://www.who.int/ethics/publications/en/">http://www.who.int/ethics/publications/en/</a>
Council of Europe	Steering Committee on Bioethics (CDBI)	<a href="http://www.coe.int/t/dg3/healthbioethic/cdbi/default_EN.asp?">http://www.coe.int/t/dg3/healthbioethic/cdbi/default_EN.asp?</a>
	Human Rights Law and Policy	<a href="http://www.coe.int/t/dghl/standardsetting/hrpolicy/other_committees/cddh-age/default_EN.asp">http://www.coe.int/t/dghl/standardsetting/hrpolicy/other_committees/cddh-age/default_EN.asp</a>
International European Commission	European Group on Ethics in Science and New Technologies	<a href="http://ec.europa.eu/european_group_ethics/index_en.htm">http://ec.europa.eu/european_group_ethics/index_en.htm</a>
Association of Bioethics		<a href="http://bioethics-international.org/index.php?show=index">http://bioethics-international.org/index.php?show=index</a>

UNESCO has available diverse reports, none of which concerns the area of aging – however, the Report “On the principle of respect for human vulnerability and personal integrity”<sup>xvi</sup> falls under the related theme.

The World Health Organization (WHO), European Region, produced, in 2011, the “European report on preventing elder maltreatment”<sup>xvii</sup>, focused on the abuse and having as fundament the existing estimates and the aging of the population in the region. Also exists one report with the related thematic within the health sphere – in particular, the Report “Ethical Choices in Long-Term Care: What Does Justice Require?”<sup>xviii</sup>.

The European Commission released, in 2014, a “Recommendation about the promotion of human right of more elderly people”<sup>xix</sup>, divulging good practices<sup>xx</sup> in the protection of the elder’s rights.

*Findings Analyses/Results*

In the previous step, researching 40 Councils, we identified 4 documents related to aging and 8 that included references to elderly people. We will proceed now to the analyses of the found documents and synthesis of the characterizing elements.

Aging as the main topic appears to us in **three opinions**, produced by the Ethic Councils of Portugal, Italy and of the United States, such as in **one text** of the Tunisian President's Committee. So, the total is **four documents**.

Chart 4 - Thematic documents about aging

Country	Council	Opinion	Year	Text Reference
Portugal	Conselho Nacional de Ética para as Ciências da Vida	<i>Parecer sobre as vulnerabilidades das pessoas idosas, em especial das que residem em instituições.</i>	2014	CNECV
Italy	Comitato Nazionale per la Bioetica	<i>Bioetica e diritti degli anziani</i> [Parecer]	2006	CNB
USA	President's Council on Bioethics	<i>Taking Care: ethical care giving in our aging society</i> [Report]	2005	PCB
Tunisia	Comité National d'Ethique Médicale	" <i>Le vieillissement</i> " [discurso]	1999	CNEM

1. **Opinion about the vulnerabilities of elderly people, especially the ones that live in institutions<sup>xxi</sup>**. National Council of Ethic to the Life Sciences, Portugal 2014

The opinion has a memo associated, "introductory reflection instrument of the opinion, the responsibility falling under its authors". In this memo are presented the contextualization, the importance of the reflection, some statistic data, the elders' situation, especially the ones in institutions, special needs on the topic of health care, a synthesis of the auditions performed, presented the idea of "new profiles of vulnerability associated with age", the juridical framework and the special characterization on situations of vulnerability. The opinion establishes them considering the warning for the vulnerabilities of elderly people, especially the ones that live in collective institutions, the gap of legal framework and the specification of health care, naming 15 recommendations, among which, the support to the families, the program of the institutions that take in elders, provide attention to the professional and human formation within the providers of well care as an "Statute of the Elder".

2. **Bioetica e diritti degli anziani**. Comitato Nazionale per la Bioetica, Italy. 2006.

A document of 41 pages with fundamentals of demographic order, of epidemiological profile, characteristics of the elder "self-sufficient" and the dependent elder. It presents the "conjunction of silence" concerning aging, identity crisis and the demand of meanings, of the self care and balance of the elders' skills. It focus on the health of an elderly people, to the diversity of the ways of aging, to the inter-generation communication and social, cultural and religious aspects, as well as the values of the elder. In the second part, it



focuses the aspects of a dependent elder, de phenomena's of aging, of the "weak elder", of the services and people like resources to the elder, about the abuse of elders. In the conclusion are presented the permits of the synthesis and the consent regarding the elder as well as some recommendations, among which are the creation of an Observatory of the Elder's Conditions and special attention to the dependent elder.

3. **Taking Care: ethical care giving in our aging society**<sup>xii</sup>. *President's Council on Bioethics*, 2005. A document with 333 pages, pausing in the first part, the dilemmas of aging in contemporary society, the trajectory of chronic disease, the need for caregivers; biological and individual nature of aging, the presence or absence of significant people, welfare and poverty, gender and individual vision of death. Then, dementia and people with a focus on Alzheimer's disease. Analyzes the "limited wisdom of advance directives," the moral problem of choosing before, consent, the living will, personal identity. Then the issue limits, either Wills or care plans. Stresses the general principles of an ethic of care, with reference to the value of human life, the meaning of human death, respect for the individual, the well being of the family and the good of society. Includes treatment and the burden of the disease as well as moral limits. Relies on the principle of prudence for difficult cases, the decision on Si and Others. The conclusions and recommendations summarize up aspects of demography, life, health and death in our society.

4. **Le vieillissement**<sup>xxiii</sup>. *Republique Tunisine*, 1999.

It is published on the Council's website, President's speech in a scientific event. File 4 pages, focused on aging, the importance of finding balance without therapeutic obstinacy without medicalization of death, while respecting the will and the refusal; proposing a discipline or gerontology specialty, to avoid reliance, keep people in their homes. "Il y a pour notre société une obligation éthique de prévention de la détérioration de la qualité de vie des personnes âgées, de leur autonomie qui est le fondement de l'éthique et le gage de la dignité de la personne. Il y a un principe éthique absolu : toute personne est respectable, indépendante de son âge, de sa santé physique et mentale. L'âge ne peut être un facteur de discrimination."<sup>xxiv</sup>

These four are the central documents that analyze to identify the principles, values and bioethical factors relating to aging. The eight opinions, focused on other issues but that made reference to the elderly and aging, divided into two thematic areas: focusing on health in general, and centered on the theme of dementia and loss of autonomy.

Chart 5 - Documents referred aging

Themes	Country	Council	Opinion	Year
Centered on health	Holland	The Netherlands Centre for Ethics and Health	Forward Look: Ethics and Health	2012
	Sweden	Swedish National Council on Medical Ethics	Ethical platform for priority setting in Health Care	2009
	Canada	Commission de l'éthique en science et en technologie	La télésanté clinique au Québec: un regard éthique	2014
	United Kingdom	Nuffield Council of Bioethics	Medical profiling and online medicine: the ethics of 'personalised healthcare' in a consumer age	2009
Centered on the theme of dementia and loss of autonomy	Germany	Deutscher Ethikrat	Dementia and self-determination	2013
	Belgium	Comité Consultatif de Bioéthique de Belgique	Règles éthiques face aux personnes atteintes de démence	2001
	Italy	Comitato Nazionale per la Bioetica	Le demenze e la malattia di Alzheimer: considerazioni etiche	2014
	United Kingdom	Nuffield Council of Bioethics	Dementia: ethical issues	2009

1. **Focused on health**, it is subdivided integrating titles like “ethics and health”, “ethics and lifestyles” priorities in health care, technology and telehealth, including home automation and robotics.

a. **Forward Look: Ethics and Health**<sup>xxv</sup>. *The Netherlands Centre for Ethics and Health*. 2012. Document of 38 pages that covers the developments in the health sector, care throughout the life cycle, changing roles of patients, care providers and health policies, globalization of health care and ethical aspects in the near future. Another part is dedicated to the issues of autonomy of patients, responsibilities of careers and solidarity in health care. Of the entire document, as regards the elderly, there are two subchapters which we highlight: “Care for the elderly”<sup>xvi</sup> focusing demographic aspects and “Medical interventions among the elderly: limits to the interventions”<sup>xvii</sup>, more focused on questions about what constitutes a “good life” and the decision-making difficulties. Dedicates a subchapter for issues of “New devices for independent living: home automation and e-health”<sup>xviii</sup>, where it is considered that the devices can help us care for the elderly.

b. **The ethical platform for priority setting in Health Care**<sup>xxix</sup>. *Swedish National Council on Medical Ethics*, 2009.

The Council commented on the proposal to amend the ethics platform<sup>xxx</sup> for setting priorities in health, that Government had done, proposing clarification / revision of the principles of ethics and add a principle of responsibility / liability by changing the hierarchy of ethical principles. The Council rejected the proposal of the Centre and offered several

arguments to show that the proposed amendments should not be approved. The Council stressed that the platform without a ranking would not offer adequate guidance for decision-making in health care and the core values of “platform” could be lost, as an “ethical platform” no hierarchy between the principles could lead to arbitrary decisions.

c. *La télésanté clinique au Québec: un regard éthique*<sup>xxxix</sup>, *Commission de l'éthique en science et en technologie*, 2014

A document of 132 pages, presenting the reality of telehealth, the principles, values, relationship to vulnerability, confidentiality and protection of privacy, as well as recommendations in each chapter. The innovation in the context of care, transforming the contexts of care, requires the protection of people in vulnerable situations, autonomy, confidentiality and respect for private life.

d. *Medical profiling and online medicine: the ethics of 'personalised healthcare' in a consumer age*<sup>xxxix</sup>. *Nuffield Council of Bioethics*, 2009.

Focusing on the issues of health information and available sources (websites) and health services by using internet, it is recognized that the elderly use more services than younger (associated with the use of the internet) and the development of IT systems in health.

## 2. Centered in dementia and loss of autonomy

a. *Dementia and self-determination*<sup>xxxix</sup>. *Deutscher Ethikrat*. 2013.

An extensive file of 107 pages, with a first part centered in the explanation of dementia, particularly Alzheimer's disease; the approach of the German social reality, considering the affected people, careers, professionals and institutions; the third chapter discusses the ethical challenge of empowering and protecting self-determination, with a speech centered on Kant, stressing that even a limited self-determination must be respected; in the fourth chapter addresses the legal framework of that have limited self-determination, followed by the identification of areas and implementation of plans to improve the situation of people with dementia (such as the National Plan and the implementation of the Convention of the rights of persons with disabilities). In the sixth chapter, we present 16 recommendations of the Council referred to the coordination of health and social efforts to care for people with dementia, policies, support to families and carers, research, strengthening of financial resources.

b. *Règles éthiques face aux personnes atteintes de démence*<sup>xxxix</sup>. *Comité Consultatif de Bioéthique de Belgique*. Avis n°14 du 10 décembre 2001.

Opinion with 39 pages, starting with a summary of the special measures of protection that requires the state of dementia, the problem of research on people unable and consent,

leaving recommendations. The clinical, dementia and senility It follows, with the ethical problems related to autonomy and the “shared dignity,” the advance directives and the administration of property. Chapter II is organized around the question: “A seriously disturbed mental state, as in Alzheimer’s disease, justifies special protective measures are taken?” The following chapter deals with the problem of experimentation in people with dementia. In both, presents the ethical-legal framework is revealed, research, the question of risk, benefit and presented consensual and non-consensual opinions.

c. *Le demenze e la malattia di Alzheimer: considerazioni etiche*<sup>xxxv</sup>. Comitato Nazionale per la Bioetica, Itália. 2014.

A 2-page file with summary and the full opinion, with 27 pages. Presents the scientific part and ethical problems, including the problem of personal identity and the difficulties to participate in decision-making processes, from informed consent to research, social, legal issues in connection to mental health.

d. *Dementia: ethical issues*<sup>xxxvi</sup>. Nuffield Council of Bioethics, 2009.

The report has 209 pages, eight chapters, executive summary and recommendations. Provides information on dementia, proposes an ethical framework, the approach by professionals, caregivers, society in general; addresses the challenges in decision making, everyday dilemmas, the importance of research, the role of society in the inclusion and support to individuals and families.

#### *Discussion and identification of the bioethics’ elements*

The significant increase in the number of older people is one of the world concerns over impact or, if one prefers, the progressive aging of the population is at the center of national and international demographic concerns. This may either be seen as a wonderful reality, increase the years that we can live, or as a problem, due to the reduction of autonomy of aging people. If it is commonly accepted that from the 60s of last century has installed a “youth culture” is important to promote an appreciation of “culture of old age”, leaving to join the old condition of the sick, unproductive, inefficient and source of reference for the community. There is a “negative perception, fair, distorted and stigmatizing of people with advanced age” (CNECV, 2014) that one must be aware to be able to change - and a change in attitude, in addition to being time consuming, lacks the foundations of a reflection ethical and humanistic.

Aging has a chronological dimension, with the majority of gerontological and geriatric literature accepts the chronological age to define the person as old - the age of sixty-five years is accepted by the World Health Organization and the United Nations. But like all biochronical limits, it seems abstract, requiring single out for each person. The demographic phenomenon of our time puts us the challenge of:

“implement educational strategies to prepare for the condition of the elderly (the gerogogia). What do you mean, however, is that the human person, with his rights and duties, holds a dignity and a wealth that should be promoted at every stage of its existence. The elderly should therefore always be considered subject to participation in the construction of society, according to the possibilities of each. In this sense, then, a mature society is called upon not to disregard individuals when they reach old age and to promote the resources of culture, transmitting values and experiences, skills and individual skills, spirituality and religiosity, in what sense can be fully understood the concept of Active Ageing <sup>xxxvii</sup>.”

And if this concept, here called, in the opinion of 2006 has become an expression actually an active and healthy aging, depends on what the elderly person chooses for you, in accordance with their conditions and circumstances. We know that:

“a significant proportion of older people inevitably evolve to dementia states or at least to an accumulation of disabling health complications that require special and expensive support. Note that, given that female longevity is larger than the male, is also in women has more serious health indicators.”<sup>xxxviii</sup>

It follows that many concerns with the elderly emerge in bioethical terms, centered at the end of life, access to health care, in health priorities, the situation of the person with dementia, the advanced directives<sup>xxxix</sup>, the importance of finding balance, without therapeutic obstinacy without medicalization of death<sup>xl</sup> - the virtuous balance of an act focused on respect for the dignity of the person.

In the three opinions on aging emerge a set of principles and bioethical elements that we consider important to identify in aggregated form:

- 1. **Human Dignity**, regardless of the stage of life where each is located; in the case of the elderly is to recognize it as being unique, with its place, that deserves respect, with their stories, doings and sayings; without discredit by their circumstance and acceptance of their way to be in life; “The human person has equal dignity at all stages of his life, a condition that must be respected especially in phases where it operates a special vulnerability” (CNECV, 2014); and it's about human dignity that all documents based ethics position;
- 2. **Recognition of the person's situation uniqueness to aging**, “equal chronological age does not mean the same vulnerabilities in the elderly” and “progressive weakness and loss of capacity, verified in a long time, is a common process but at the same time, singular, in people's lives as they age” (CNECV, 2014); we highlight the sense of “to grow old” as a dynamic process, changing, circumstantial;

- 3. **Free decision** of the self that materializes the **Respect for autonomy**, it is for others; power to make their decisions upon himself, to accept or refuse health care; often affected by social and family perceptions, the myths about the inability of the elderly, the will to replace the elderly in their decisions about your life (CNEM, 1999). Important to preserve the freedom and autonomy of the elderly, respect their beliefs and values, it is important to evaluate the person's decision-making capacity; often, for lack of information or reflection, family change the environment of the elderly, mischaracterize the space, control spending, which creates dependency and increases the vulnerability (CNB, 2006); The sense of respect the autonomy that exists or that presents itself is a common element to all documents;
- 4. **Recognition of the vulnerabilities** of older people, who appear as such in vulnerable groups<sup>xli</sup>, but because, by living more years, will experiencing progressive debilitation, losing the capacity for autonomy in daily life; so it is considered that vulnerabilities can be aggravated or face the institutionalization or the deterioration of health status but also the way society and people interact with the elderly; This is another common principle in all documents,
- 5. **Requirement ethics and social responsibility in monitoring the elderly**, "recognition due to the contribution of people to society throughout their lives and the appreciation of their participation in this follows the design provide the elderly with the best possible conditions" (CNECV, 2014); appears both expressed support for families who do not have conditions to care for people with addictions, as related to the duty of the State and society, of being responsible for taking care of the community, acting in favor of this, defending the rights of the elderly (PCB 2005)
- 6. **Non-discrimination by age**, refusing bias, prejudice and stereotypes of aging, which adversely impacted the people, especially among elderly; "There is an absolute ethical principle: every person is respected, regardless of their age, their physical and mental health age cannot be a factor of discrimination."<sup>xliii</sup> (CNEM, 1999)
- 7. **Guidance for the integral good and the quality of life** and prevention of deterioration, understood as "ethical obligation of society" (CNEM, 1999), it is recommended that "public policies for the elderly are not of purely assistance content but oriented to the conditions of realization of their full well, considering their active participation in social life" (CNECV, 2014).

Overall, integrating the advice on which the aging arises, there is a focus on dementia and associated losses or identity or personality, social, affective. "Think about dementia makes us question our own image of humanity."<sup>xliii</sup>

But there is also a focus on the redirect to the resources that the person still has to the capabilities that are present. That is:

“change the approach (...) attention to their skill and energy actually available, requires a project that includes: a different anthropological basis for old age definition, a new psycho-pedagogical competence to identify asset resources to intervene, a social network and health duly motivated and competent”<sup>xliv</sup>.

One of the main problems of interest to bioethics, is the concern about “the limits of viability or not self-reliance of the elderly, called frail elderly, especially where there is support for the family and there is no uncertain economic conditions”<sup>xlv</sup>. The equation in which the elderly is similar to invalid patient, according to the classic aphorism “senectus ipsa morbus”, is still the dominant attitude; neglect and ignorance, leading to confuse the pace of old age with still manageable chronic disease, may be responsible for loss of self-sufficiency and social costs and very high human. It is also considered loneliness - from widowhood, loss of children and families - and poverty as especially complex, more in large metropolitan cities, which may favor “of marginalization or self-marginalization, especially in older people can live vegetating, patients commit suicide, die on the street or in a position of material and moral degradation”<sup>xlvi</sup>.

In common, the documents of the National Ethics Councils have a similar design and anthropology ethics:

“Si può riassumere il contesto di questi diritti nelle seguenti proposizioni: l’anziano è persona e come tale va rispettato; l’anziano ha diritto e dovere di promuovere le proprie risorse umane e in particolare spirituali; la società ha il dovere etico di facilitare la promozione della dignità di vita della persona anziana; l’anziano ha diritto di essere trattato secondo i principi di equità e giustizia, indipendentemente dal suo grado di autonomia e di salute.”<sup>xlvii</sup>

“Human beings who are dwindling, enfeebled, or disabled in body or in mind remain equal members of the human community. As such, we are obligated to treat them with respect and to seek their well-being, here and now. We should always seek to benefit the life incapacitated persons still have, and never treat even the most diminished individuals as unworthy of our company and care.”<sup>xlviii</sup>

Among the instruments to deal with difficult decisions at the end of life, are the advance directives of the will, which enable express individual preferences when becoming disabled (“living will”) or indicate one care provider, to decide on their behalf. This seems to be a more sensible option for adjusting to the case, because trying to define in precise terms

the future will can be misunderstood or not effective (PCBs, p. 203). In other words, while referring to living wills is preferred to be conducted or not conducted, it is preferable to specify who makes decisions on behalf of the person.

The goal of the **ethical care** is not to extend or postpone the end of life or to shorten people's lives - understanding that we must take good care "of the needs and interests of people unable to care for themselves, we must stand up and defend certain moral limits prevent us from violating the people entrusted to our care: No to euthanasia, not the assisted suicide."<sup>xlix</sup>

The lighter ethical reasons to forgo life-sustaining treatments are a must to avoid treatments that are disproportionate or futile. In addition to legal instruments, we need to develop policies and procedures to encourage discussion and permanent coordination among all parties involved, including family members, health professionals, social service providers and, wherever possible, their own.

Two relevant philosophical principles emerge, with regard to care for the elderly: respect for every human life, no matter how it may seem to be diminished (and it follows the immorality of causing death to people) and the moral understanding that there are limits the interventions - life is a good but not the only one; "we have to let go, especially at a time when the imperative of relentless use of the available technology passes the default position"; so do not start or stop treatment is justified on ethical perspective.

The aging, old age, disease and the process of dying are not friendly topics, dir would; but can be addressed from the perspective of the resources that the person still has. Denial is not an option, "a mature and preoccupied society does not hesitate to assume their responsibilities"<sup>1</sup>.

The recommendation "that the elderly can remain, as much time as possible in their usual environment with respective space environment, psychological, emotional and relational" (CNECV) aims to protect the vulnerabilities that are considered possibly aggravated by living in institutions, especially if this is not your will. And being in need, "**which is specially safeguarded respect for personal identity and freedom** of decision of the elderly living in collective institution, especially with regard to the use of own clothes and personal effects, and the possibility to receive or refuse visits" (CNECV).

Just because ages, human beings do not necessarily lose their capacity - reducing the human aging to a biological component would conceal the social and psycho affective, cultural and spiritual dimensions.



## CONCLUSIONS

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“Our unprecedented situation”<sup>li</sup> and “our uncertain future” require ethical and fair public policy commitments. The demographic phenomenon<sup>lii</sup> of our time requires an ethical approach, existential and human, that is its own. And if, in general, longevity is part of the aspirations of the people, fairness requires that it be accompanied by the necessary conditions to maintain quality of life. The aging process varies with people or, to put it another way, people do not age all at the same time or in the same way, not only genetic but also the social, the way of life, the environment, experiences, affective relationships.

An aging with a positive outlook requires to be ensured for the elderly, the opportunity to participate in issues of social, political, cultural, spiritual. Thus, they ensure and respect the values of freedom and equality and citizenship rights, promoting the development of a more just country. Although we are “far from robust aging bioethics”<sup>liii</sup>, there bioethical thought about aging and principles and values that emerge from the documents produced, from the looks of Ethics Councils.

The Councils have proposed to draw attention and reflection of public opinion to the condition of the old man / elder in the current situation (CNB, p.4); run all of the demographic, epidemiological profile, the self-sufficient elderly and residing in institutions. Everyone agrees that the age has its own traits - the “true identity crisis: is at stake our own image”<sup>liiv</sup> - and that it would revert to a “culture of old age”, respect for the elderly and promotion of a positive aging. Given the prospect of aging, “we conclude that we may face in the coming years, a genuine crisis of care, with more dependents in need of long-term care and fewer people available to take care”<sup>liv</sup>.

Highlights the diversity of modes of aging and the importance of preparing all for aging (which begins, after all, from pregnancy and childhood), with the promotion of literacy for aging, creating elements social and legal protectors (the Elderly Statute, Observatory of the Elderly conditions, more legal protection, among other suggestions of opinions), the identification and intervention in abuse situations. The value of human life matters associate reflection on the meaning of the end of human life, proposing a discipline or specialty gerontology, ways to avoid dependency and keep people in their environments (households).

The analysis of opinions on aging emerged a set of principles and bioethical elements synthesized: [1] respect for human dignity, regardless of the stage of life where each is located; [2] recognition of the person’s situation uniqueness to aging; [3] freedom of one’s own decision, which is materialized in respect for autonomy, it is for others; [4] recognition of the vulnerabilities of the elderly, [5] ethical requirement and social responsibility in

monitoring the elderly, [6] non-discrimination by age and [7] the guidance to the conditions of the integral good and the quality of life.

A person who's aging tells the progressive loneliness that is finding, usually by two different types of loss: sensory and vital capacity as well as for loss or removal of those beings who know and before which appears. Arendt wrote in 1973, in a letter to Mary McCarthy, who "age means the gradual transformation (or rather sudden) of a world of familiar faces (either friends or enemies) in a desert species inhabited by strange faces. In other words, not I who retreat from the world to me, is the world falls apart."<sup>1vi</sup> It is no accident that Arendt makes the description of an individual's life as a flower that gradually opens in daylight, blossoming until the culmination and progressive loss to extinction, and the time to adulthood is a progressive rise as aging is a gradual withdrawal.

Aging also in bioethical reflection, carries a progressive deletion of the world for the extinction of known viewers and lack of self-demonstration. An existential circumstance for which we can prepare, on the assumption that an elderly person has a longer life experience, with actions and sufferings, losses and projects, sorrows and joys, successes and failures, and that human life in its longevity, interweaves those who are older and those younger, calling us on the crucial issue of human existence.

## ENDNOTES

<sup>i</sup>Almost all Council have, as in Spain, Declaración sobre la atención al final de la vida (2013), the Avis of Belgian Council “Fin de vie, autonomie de la personne, volonté de mourir.” (2013), the publications of Danish Council “Ethical challenges in the end of life” (2008) or “The debate that never dies - euthanasia and ethics” (2010); from Finish Council “Position: Human Dignity, Hospice Care and Euthanasia” (2012) and the Dutch Council “Terminal sedation” (2004).

<sup>ii</sup>In some committees are the ones that are available in English, as in the National Medical Ethics Committee of Slovenia website. In many countries there is a specific national Council for clinical research.

<sup>iii</sup>As with the opinion of the Austrian Committee - Research on persons without the capacity to consent—with special consideration of the concept of risk. <http://www.bundeskanzleramt.at/DocView.axd?CobId=52286>

<sup>iv</sup>That exist in some Councils as in Belgium, “Recours aux techniques biomédicales en vue de « neuro-amélioration » chez la personne non malade: enjeux éthiques” (2014); in Hellenic Council “Human Enhancement - Effect on Cognitive and Mental State” (2013); in Italian Council “Diritti umani, etica medica e tecnologia di potenziamento (enhancement) in ambito militare” (2013) or in French Council “Opinion 122 The Use of Biomedical Techniques for “Neuroenhancement” in Healthy Individuals: Ethical Issues (2012) .

<sup>v</sup>This is the case the opinion of the Danish Council “Recommendations concerning Social Robots”(2010)

<sup>vi</sup>As in Danish Council “Recycling the Body - Organ Donation and Ethics”(2010) <http://www.etiskraad.dk/Udgivelser.aspx>

<sup>vii</sup>Look at some examples: Ethics of voluntary activities ( 2014), Needs for amendments in act on legal recognition of the gender of transsexuals (17 April, 2013), Statement on Final Report by a Working Group on Functional Child Welfare and a proposal for a quality recommendation for child welfare (25 September, 2013), Position on the status and treatment of undocumented immigrants (6 November, 2013), Examinations of sexual identity in minors (26 September, 2011), Surrogacy treatment in Finland (28 September, 2011), Opinion on the report on the care of respiratory paralysis patients, (26.3.2007), Statement on resuscitation and intensive care of children with serious intellectual disabilities (4.4.2007). <http://www.etene.fi/en/materials/statements>

<sup>viii</sup>Look at some examples from Hellenic National Bioethics Commission - Contemporary issues of “Choices” in reproduction, Patients Associations: A report on the medical ethics issues that patients face in our country, Management and Burial of Embryos Less Than 180 Days of Gestation, Human Body Parts and Cadaveric Preparations, Control of Non-

Invasive Clinical Trials for Drugs, Binding of Do-Not-Resuscitate Orders (DNRs), Human Enhancement - Effect on Cognitive and Mental State, Control of Medically Assisted Human Reproduction, Protecting Animals Used for Scientific Purposes, Direct-To-Consumer (DTC) Genetic Testing, Conflict Of Interest In Biomedical Research, Transmissible Infectious Diseases: Public Health And Autonomy, Consent In The Patient-Physician Relationship, Management of Biological Wealth, Genetic Data In Private Insurance, Prenatal And Pre-Implantation Diagnosis, Umbilical Cord Blood Banking, Human Biobanks, Artificial Prolongation Of Life, Transplantation, Ethics commissions, Patents in Biotechnology, Cloning, Medically Assisted Human Reproduction, Stem Cells In Biomedicine and Clinical Medicine.

<sup>ix</sup> We do not consider here ethical aspects of egg freezing in anticipation of a infertility linked to age - “Avis n° 57 du 16 décembre 2013 relatif aux aspects éthiques de la congélation des ovules en prévision d’une infertilité liée à l’âge”

<sup>x</sup> Commission Consultative Nationale d’Éthique pour les sciences de la Vie et de la Santé, self designated Commission Nationale d’Éthique - Avis 1990, concernant à la protection de la jeunesse.

<sup>xi</sup>

<sup>xii</sup> Avis n° 4 : 26 Janvier 1999 Éthique - progres technologiques - depenses de sante.

<sup>xiii</sup> La Procréation Médicalement Assistée, La Création Des Comités D’éthique Locaux, Le Clonage, Éthique – Progrès Technologiques – Dépenses De Santé, Clonage thérapeutique, Gestion de tissus d’embryons, de fœtus et de corps d’enfants morts-nés ou décédés au cours de la période néonatale. Prélèvement d’organes et de tissus sur cadavres « médico-légaux ». Le VIH-SIDA, problèmes éthiques et juridiques. l’interruption medicale de la grossesse.

<sup>xiv</sup> É o caso de “ Bioethics Commission Develops Ethical Framework—Guidance for National-Level Review of Higher Risk Pediatric Research Protocols” ou “ Safeguarding Children: Pediatric Medical Countermeasure Research (Mar, 2013)

<sup>xv</sup> [https://bioethicsarchive.georgetown.edu/pcbe/reports/taking\\_care/](https://bioethicsarchive.georgetown.edu/pcbe/reports/taking_care/)

<sup>xvi</sup> United Nations Educational, Scientific and Cultural Organization (UNESCO) 2013. Report Of The International Bioethics Committee Of UNESCO On The Principle Of Respect For Human Vulnerability And Personal Integrity. ISBN 978-92-3-001111-6. Disponível em <http://unesdoc.unesco.org/images/0021/002194/219494E.pdf>

<sup>xvii</sup> Abstract: “Elder maltreatment is pervasive in all countries in the WHO European Region, and estimates suggest that at least 4 million people in the Region experience elder maltreatment in any one year. Most countries in the Region have an ageing population, and one third of the population is forecast to be 60 years and older in 2050, putting more people at risk of elder maltreatment. Elder maltreatment has far-reaching consequences for the mental and physical well-being of tens of millions of older people, and if left unchecked

will result in their premature death. Estimates suggest that about 2500 older people may lose their lives annually from elder maltreatment. The report highlights the numerous biological, social, cultural, economic and environmental factors that interact to influence the risk and protective factors of being a victim or perpetrator of elder maltreatment. There is some evidence of effectiveness, and examples include psychological programs for perpetrators and programs designed to change attitudes towards older people, improve the mental health of caregivers and, in earlier life, to promote nurturing relationships and social skills learning. The evidence base needs to be strengthened, but much can be done by implementing interventions using an evaluative framework. Prevention and social justice for older people can only be achieved by mainstreaming this response into health and social policy. Surveys show that the public and policy-makers are increasingly concerned about the problem, and the policy response needs to be strengthened to meet this demand". In European report on preventing elder maltreatment. Em [http://www.coe.int/t/dghl/standardsetting/hrpolicy/other\\_committees/cddh-age/Document\\_CDDH\\_AGE/european-report-preventing-elder-maltreatment.pdf](http://www.coe.int/t/dghl/standardsetting/hrpolicy/other_committees/cddh-age/Document_CDDH_AGE/european-report-preventing-elder-maltreatment.pdf)

<sup>xvii</sup> Cf. [http://www.who.int/mediacentre/news/notes/ethical\\_choices.pdf?ua=1](http://www.who.int/mediacentre/news/notes/ethical_choices.pdf?ua=1)

<sup>xix</sup> European Committee. Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of the human rights of older persons (Adopted by the Committee of Ministers on 19 February 2014 at the 1192nd meeting of the Ministers' Deputies

<sup>xx</sup> "Compendium of good practices" ([http://www.coe.int/t/dghl/standardsetting/hrpolicy/other\\_committees/cddh-age/Document\\_CDDH\\_AGE/CDDH-AGE%282013%2904rev2.pdf](http://www.coe.int/t/dghl/standardsetting/hrpolicy/other_committees/cddh-age/Document_CDDH_AGE/CDDH-AGE%282013%2904rev2.pdf)) e um site com as boas práticas por país: [http://www.coe.int/t/dghl/standardsetting/hrpolicy/other\\_committees/cddh-age/AGE\\_goodpractices.asp](http://www.coe.int/t/dghl/standardsetting/hrpolicy/other_committees/cddh-age/AGE_goodpractices.asp)

<sup>xxi</sup> CONSELHO NACIONAL DE ÉTICA PARA AS CIÊNCIAS DA VIDA. 80/CNECV/2014 Parecer sobre as vulnerabilidades das pessoas idosas, em especial das que residem em instituições (Julho de 2014). Disponível em <http://www.cnecv.pt>.

<sup>xxii</sup> Available in [https://bioethicsarchive.georgetown.edu/pcbe/reports/taking\\_care/](https://bioethicsarchive.georgetown.edu/pcbe/reports/taking_care/)

<sup>xxiii</sup> Available in

[http://www.comiteethique.rns.tn/ethique/CONFERENCES\\_ET\\_PUBLICATIONS/VIEILLISSEMENT.pdf](http://www.comiteethique.rns.tn/ethique/CONFERENCES_ET_PUBLICATIONS/VIEILLISSEMENT.pdf)

<sup>xiv</sup> Idem, p.3.

<sup>xxv</sup> Available in [http://www.ceg.nl/uploads/publicaties/Forward\\_Look\\_Ethics\\_and\\_Health.pdf](http://www.ceg.nl/uploads/publicaties/Forward_Look_Ethics_and_Health.pdf)

<sup>xxvi</sup> "People live longer and live more years of life without (major) disabilities. However, towards the end of life, elderly often face multiple health problems. About half of people over the age of 65 live with one or more chronic condition. In the years to come, the number of elderly people and life expectancy will continue to increase in the Netherlands. According to estimates by Statistics Netherlands, the number of people over the age of

65 will rise from 2.6 million (16% of the population) in 2010 to 4.5 million (25% of the population) by 2050. Not only the amount but also the percentage of elderly people will rise (Statistics Netherlands 2010). This demographic development increases the scale and urgency of the (ethical) questions of elderly care. Care consumption will increase as the number of elderly people rises, which will challenge both the medical sector and other social domains, as they are not yet prepared to deal with such an increase in this population (RVZ 2012). These questions are not only of medical interest, but also relate to care arrangements and the living environment that are required to provide the elderly with the opportunity to lead a pleasant (independent) life. How do people want to grow old in this society?" Idem, p.12.

<sup>xxvii</sup> "There is a growing understanding of the limits to medical intervention in the elderly. At the same time, there is a great deal of attention for the health gains that can still be achieved for the elderly, for example by prevention. The medical ethical dilemma between intervention on the one hand and a wait-and-see approach on the other is especially pressing for the very old, particularly as they become increasingly vulnerable. What constitutes good, fitting care for the elderly? How should doctors deal with comorbidity and frailty? There are many differences between elderly individuals, this raises questions about the role of diversity. Which notions about what constitutes a 'good life' precede such considerations? A development that underpins the urgency of these questions is the rising age limit for consideration for (high risk) surgery. Raising the limits for interventions is a result of progress in the field of surgery, as well as improved multidisciplinary cooperation (for example with anaesthesiology). Patients will have to make difficult decisions, in close consultation with care professionals, about whether or not interventions are desirable for them. It is particularly complex what the role of family and partners of dementia patients should be in taking decisions. The debate about limits to interventions also touches upon issues of care distribution, and will gain importance in the future; to what degree are we, as a society, willing to invest in (improving care for) the elderly?" Idem, p.13.

<sup>xxviii</sup> "The use of technological devices and systems such as domotics (technology in the home), robotics, e-health and telecare is increasing. New technologies allow patients to be monitored or coached remotely, for example by using a webcam or with electronic sensors that measure patients' body function (RVZ/CEG 2010(...)) These technologies may be deployed to ease the burden of professional care for the elderly, for example. Some see it as a good way to compensate for financial and staffing shortages. However, particularly for the elderly, striking a balance between technological support (focused on self-sufficiency) and the provision of personalized care by care providers and/or informal carers is a difficult balance. How does the implementation of technological devices address the needs of the group of elderly people for whom a lack of personal care (loneliness) is the primary issue?" p.14

<sup>xix</sup> Available in <http://www.smer.se/opinions/the-ethical-platform-for-priority-setting-in-health-care/>. See National Model for Transparent Prioritisation in Swedish Health Care. Revised Version. 2011. In <http://www.diva-portal.org/smash/get/diva2:759770/FULLTEXT01.pdf>

<sup>xxx</sup> The “ethical platform ‘for the priorities in health care had been approved by parliament (Riksdagen) in 1997. It is based on the principles of human dignity, solidarity and needs and cost-effectiveness. “The three principles have a joint ranking placing the principle of human dignity first, followed by the principle of needs and solidarity, followed by the principle of cost effectiveness. Since the principle of needs and solidarity precedes the cost-effectiveness principle, severe diseases and substantial deterioration or inequality of life should take priority over the less severe, even though treating severe conditions may cost substantially more. Hence, the principle of cost-effectiveness cannot be used to deny care or offer a lower quality of care, e.g. to the dying, severely and chronically ill, elderly, functionally disabled or others for whom delivering care would not be “profitable” Idem, p. 3.

<sup>xxxi</sup> Available in

[http://www.ethique.gouv.qc.ca/fr/assets/documents/Telesante/Telesante\\_avis\\_A.pdf](http://www.ethique.gouv.qc.ca/fr/assets/documents/Telesante/Telesante_avis_A.pdf)

<sup>xxxii</sup> Available in

<http://nuffieldbioethics.org/wp-content/uploads/2014/07/Medical-profiling-and-online-medicine-the-ethics-of-personalised-healthcare-in-a-consumer-age-Web-version-reduced.pdf>.

<sup>xxxiii</sup> Available in

<http://www.ethikrat.org/files/opinion-dementia-and-self-determination.pdf>

<sup>xxxiv</sup> Available in

[http://www.health.belgium.be/filestore/7956421\\_FR/avis14-annexe\\_7956421\\_fr.pdf](http://www.health.belgium.be/filestore/7956421_FR/avis14-annexe_7956421_fr.pdf)

<sup>xxxv</sup> Available in <http://www.palazzochigi.it/bioetica/pareri.html>

<sup>xxxvi</sup> Available in

<http://nuffieldbioethics.org/wp-content/uploads/2014/07/Dementia-report-Oct-09.pdf>

<sup>xxxvii</sup> Comitato Nazionale per la Bioetica, Italy. 2006. Bioetica e diritti degli anziani. “Di più, una società altamente civilizzata è quella che mette in atto strategie pedagogiche per prepararsi alla condizione anziana (la c.d. geragogia). Quel che si vuole affermare, invece, è che la persona umana, con i suoi diritti e doveri, è titolare di una dignità e di una ricchezza che devono essere promosse in ogni fase della propria esistenza. L’anziano va dunque considerato sempre soggetto di partecipazione alla costruzione della società, secondo le possibilità di ciascuno. In tal senso, allora una società matura è chiamata a non tralasciar eisoggetti quando raggiungono l’anzianità ben sì a promuoverne le risorse di cultura, di trasmissione di valori e di vissuti, di abilità e capacità attuali individuali, di spiritualità e religiosità: in tal senso può intendersi compiutamente il concetto di Active Aging.” p. 14 (o sublinhado é nosso)

<sup>xxxviii</sup> Memorandum CNECV, 2014, p. 4. The “healthy life expectancy” which, according to the Instituto Nacional de Estadística (Nations Statistics Institute), is 60.7 years for men and 58.7 years for women. Crossing this data with on the average life expectancy, we points to a lifetime expectedly “unhealthy” of 11 years for men and 22 years for women.

<sup>xxxix</sup> Appears in all documents, such as a person’s will instrument of knowledge when it becomes incompetent or unable to decide on them. In *Taking Care: ethical care giving in our aging society*, is referred the “wisdom of advanced directives”

<sup>xl</sup> Very clear in documents of PCB, *Taking Care*, and in *Le vieillissement*, Tunisia.

<sup>xli</sup> For example - “In the context of pandemics, in contrast, the stakes involved are different, because the risks and costs are distributed very unevenly. Because pandemics span over a relatively limited period of time, and because they do not only affect a sub-group of the population (e.g. compared to those who participate in a biobank) but the population in its entirety, risks and stakes are very diverse: as a healthy young person without children, for example, I may be far less worried about the ‘worst case’ of contracting this disease than an elderly person, a person with a weak immune system, or a parent (the indicators for whom is at particularly high risk are of course different for every disease).” Nuffield Council of Bioethics (2011) *Solidarity: reflections on an emerging concept in bioethics* p. 73. [http://nuffieldbioethics.org/wp-content/uploads/2014/07/Solidarity\\_report\\_FINAL.pdf](http://nuffieldbioethics.org/wp-content/uploads/2014/07/Solidarity_report_FINAL.pdf)

<sup>xlii</sup> “Il y a pour notre société une obligation éthique de prévention de la détérioration de la qualité de vie des personnes âgées, de leur autonomie qui est le fondement de l’éthique et le gage de la dignité de la personne. Il y a un principe éthique absolu : toute personne est respectable, indépendante de son âge, de sa santé physique et mentale. L’âge ne peut être un facteur de discrimination.” (CNEM, 1999, p. 3)

<sup>xliii</sup> Nuffield Council, *Dementia and self-determination*, p. 9 “Thinking about dementia makes us question our own image of humanity. If we equate a person with his or her mental performance, we must see dementia as the destroyer of the person. But if we see a person not only as a thinking being, but also as one with feelings and an emotional and social component, it is easier to direct our attention to the resources that are still present. This new perspective must be reinforced, because preserving the remaining independence and self-determination of persons with dementia, alongside medical, nursing, psychological and social support, may contribute to a greater quality of life, may have a positive influence on the course of the illness and may alleviate the emotional burdens on family members who are carers and on professional care workers. This is not intended to trivialize the illness nor to dramatize it.”

<sup>xliv</sup> “Modificare l’approccio all’anziano de medicalizzandolo e implementando invece l’attenzione alle sue capacità e alle energie effettivamente disponibili, richiede un progetto che prevede: una diversa base antropologica per la definizione della vecchiaia, una nuova competenza psico-pedagogica per identificare le risorse attive su cui intervenire, una rete



socio-sanitaria adeguatamente motivata e competente” CNB, 2006, p.15.

<sup>xlv</sup> I maggiori problemi, anche di interesse bioetico, riguardano gli anziani ai limiti della autosufficienza o non autosufficienti, i cosiddetti anziani fragili, soprattutto ove manchino il supporto della famiglia e sussistano condizioni economiche precarie. Nel nostro Paese l'equazione secondo la quale l'anziano è di per se stesso assimilabile al malato o all'invalido secondo il classico aforisma “senectus ipsa morbus”, nei fatti non sembra pienamente superata, quanto meno sotto il profilo strettamente psicologico. È infatti ancora dominante l'atteggiamento di chi ritiene le malattie del vecchio conseguenza dell'invecchiamento e spesso destinate a evolvere fatalmente. La trascuratezza e l'ignoranza portano a confondere l'incedere della vecchiaia con patologie ancora trattabili che, se non diagnosticate e curate, possono essere responsabili della perdita dell'autosufficienza e di costi sociali e umani elevatissimi.” CNB, 2006, p. 27.

<sup>xlvi</sup> “La solitudine può nascere dalla vedovanza, dalla perdita dei figli e della famiglia, dalla povertà; sono soprattutto le complesse eterogenee dinamiche delle grandi città metropolitane a favorire fenomeni di emarginazione o di autoemarginazione soprattutto nelle persone anziane che possono vivere vegetando, ammalarsi, suicidarsi, morire per strada o in condizioni di degrado materiale e morale” CNB, 2006, p. 33.

<sup>xlvii</sup> Free translate: “Pode-se resumir o contexto desses direitos nas seguintes proposições: l'anziano é uma pessoa e, como tal, deve ser respeitado; l'anziano tem o direito eo dever de promover os seus recursos humanos e, em particular, espiritual; a empresa tem o dever ético de facilitar a promoção da dignidade da vida a pessoa mais velha; l' 'mais velho tem o direito de ser tratados de acordo com os princípios da equidade e da justiça, independentemente seu grau de autonomia e saúde.” CNB, p. 37

<sup>xlviii</sup> Free translate: “Os seres humanos que estão em declínio, enfraquecidos ou desabilitados no corpo ou na mente continuam a ser membros iguais da comunidade humana. Como tal, somos obrigados a tratá-los com respeito e a procurar o seu bem-estar, aqui e agora. Nós devemos sempre procurar beneficiar a vida que as pessoas incapacitadas ainda têm e nunca tratar até mesmo o indivíduo mais diminuído como indigno da nossa companhia e cuidado”. PCB, p. 210.

<sup>xlix</sup> If we are to care well for the needs and interests of persons incapable of caring for themselves, we must erect and defend certain moral boundaries that prevent us from violating the people entrusted to our care: No euthanasia, no assisted suicide.” PCB, p. 212.

<sup>l</sup> “Aging, dementia, and dying, we are well aware, are not the cheeriest of topics. We recognize that it would be much more pleasant to look the other way and perhaps much easier to treat the topic in purely economic terms. But denial is not an option, and much more than money is at stake. Millions of American families already know the score and are struggling, often magnificently, to do the right thing for their loved ones, all on their own.

It remains for the nation to acknowledge the need and rise to meet it. A mature and caring nation, concerned about staying human in a technological age, will not shy away from its responsibilities. If asked, "Who cares?" the answer must be, "We do". (PCB, p. 222)

<sup>li</sup> PCB, Taking Care, p. 205

<sup>lii</sup> The demographic phenomenon we live in today is both enlargement and reduction on top at the base of the age pyramid; according to WHO, in 2025 there will be over one billion people with more than 60 years, and in 2050 it is expected that these figures will double. Thus, the aging population is a finding - in Portugal, more than a million and a half Portuguese are already beyond 65 years; between 2020 and 2025 the elderly can reach about 18% of the population, while young people will walk by 16%. We have now much older, either as a proportion of the total population in absolute terms - this increase has become worrying in a context where a number of other factors (such as the instability of family forms, non-availability of family to support, the crisis of social protection systems, depersonalization of social relations) aggravate the living conditions of older; the departure of so-called "productive sectors of society" refers them to a position and an unfavourable social status.

<sup>liii</sup> Agich, George (2011) Envelhecimento: um desafio para o século 21. Revista Bioethikos, Centro Universitário São Camilo; 5(3):282-290.

<sup>liv</sup> we concluded that we may face, in the coming years, a genuine caregiving crisis, with many more dependent persons in need of long-term care and fewer available people to care for them." PCB, p.203.

<sup>lvi</sup> Young-Bruehl, E. (1982) Hannah Arendt. For Love of the World. London: Yale University Press. p. 440.

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