

Standing Committees for

- the European Medical Research Councils (EMRC)
- Humanities (SCH)
- Social Sciences (SCSS)

ESF Exploratory Workshop on

Advance Directives: Towards a Coordinated European Perspective?

Zurich, Switzerland, 18-22 June 2008

Convened by:

Susanne Brauer, Roberto Andorno and Nikola Biller-Andorno

① Institute of Biomedical Ethics, Center for Ethics, University of Zurich, Switzerland

Co-sponsored by



1. Executive Summary:

General information

The ESF exploratory workshop on “Advance Directives: towards a Coordinated European Perspective” was convened by Susanne Brauer, Roberto Andorno, and Nikola Biller-Andorno from the Institute of Biomedical Ethics, University of Zurich, Switzerland (18-22 June 2008). The workshop brought together 26 established and younger scholars from 19 European countries and the USA. Two ESF representatives attended the workshop as well. The duration of the workshop was three full days.

In order to guarantee ample time for discussion, the convenors decided to provide participants with crucial empirical information on advance directives of each represented country prior to the workshop. The participants were asked to fill out an abstract form designed by the convenors. All abstracts were gathered together in a “Book of Abstracts” that was sent to the participants before the workshop along with the request of reading it carefully. A revised version of this document is on-line available as “Country reports on advance directives” at the following website: <http://www.ethik.uzh.ch/ibme/en/>
A “Book of CV” was also sent to the participants prior to the workshop.

Procedure of the workshop

1 day of the workshop

The purpose of the first day was to achieve common grounds of empirical knowledge of diverse national advance directives practices. The task was to elaborate the status quo of the legal, regulatory and clinical practices of advance directives in the participants’ countries of origin, as well as the status quo of bioethical debates in those countries. The “Book of Abstracts” supplied participants with an overview of the state of advance directives in various European countries prior to the workshop. It served as a departure point for further discussions during the entire workshop. On the first day participants were asked to give a five-minutes summary of their abstract. Additional 10 minutes were reserved for questions and discussions. These discussions also demonstrated which issues were crucial regarding the workshop topic – and should be worked on in greater detail the following workshop days.

2nd day of the workshop

The second day was fully dedicated to work in three workshop groups. The first group was focussing on normative questions, the second group on clinical practice issues and the third

group on legal problems. The convenors had designed the working sheets and assigned chairs as well as participants to each working group. Their decisions were based on a prior query in which participants were asked to report three topics regarding advance directives from a cross-cultural perspective they found to be the most important ones. The task for each group was to work on a presentation of their discussion results for the third day.

3rd day of the workshop

On the third day each working group gave a powerpoint presentation of their results of the previous day. After extended discussions of these results the workshop was concluded with considerations of future collaboration projects. For this purpose each participant was asked to present his or her research interests and possible resources and infrastructure in the light of the past discussions of the workshop. Also the various ideas of publications of the workshop results were discussed.

2. Scientific content of the event

Main Objectives of the Workshop:

The aim of the workshop was to venture into the possibility of a cross-cultural perspective on ethical and legal problems of advance directives, including related issues of implementation and policy-making. Exploring such cross-cultural perspective becomes increasingly important as citizens from European countries have growing opportunities to receive health care services outside their own countries of origin. This prompts the question whether a coordinated European approach to the role and value of advance directives is required.

The workshop followed three strands of enquiry:

- It is far from clear if there is a truly cross-cultural consensus on the moral adequacy and practical necessity of advance directives. In health care systems that rely more on familial or paternalistic decision-making structures advance directives may seem superfluous or at best unimportant. Pinpointing such differences can help to spell out disagreements about underlying justificatory bases of global bioethics, most prominently about the role of (individual) patient autonomy, which may not be as unequivocally accepted as they seem to be at first sight.

- Even where a minimal ethical consensus on advance directives seems to have emerged, important questions remain unanswered. In Europe, such a minimal consensus has been formulated in the “Convention on Human Rights and Biomedicine” (Oviedo, 1997). According to paragraph 9, “previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account.” However, the convention is silent on crucial questions regarding the scope and the binding force of advance directives. If it is (culturally and politically) manageable and (ethically) required to try and reach a more substantial agreement beyond a minimal consensus, however, is a matter of current debates.
- The complexity and diversity of approaches to advance directives concern not only merely formal, but also substantive issues, especially at the point of clinical implementation. Clinical practices in various countries reflect local, regional, and national standards that themselves reflect differences in moral, ethnic, cultural, and religious commitments. Such diversity has been echoed, for instance, in different standards for the provision of artificial nutrition and hydration, which leads also to practical challenges that are faced in implementation. Practically, patients’ wishes cannot always hold, because laws and policies may prevent or thwart their enactment. It is important to reach a clear understanding of the implications of the different normative frameworks and/or policy choices for health care practices, including potential conflicts in standards between patients’ countries of origin and the countries in which they are seeking health care.

Selected results of discussions:

All participants agreed that the **Oviedo convention article 9** is the appropriate departing point in order to think about a cross-culture agreement on advance directives in Europe. Discussions on this article showed that one party considered the convention to be powerful, although the expression of “taking” the patient’s prior wishes “into account” might be too vague. Because of great social, political, economic and cultural differences between European countries Europe is not ready yet to move further to a more substantial agreement on advance directives. Such agreement might be possible in the future. However, an agreement could also be formulated outside the Oviedo convention.

More sceptical on the use and scope of article 9 was another group of the workshop. This group announced a need for a more substantial agreement in ethical, legal and political respect. Firstly, from an ethical standpoint, the document is in need to clarify its terminology

(e.g. do patient's "wishes" encompass values and goals?). Also the convention (or the explanatory report to the convention) needs greater clarity on the significance and respect for autonomy, as well as clarification on approach of decision-making for patients without a surrogate. Additionally, the medical focus of the convention should be broadened to a care focus. From a legal perspective the group suggested that patient's preferences should be binding, not only "taking into account". Also the convention should state the opportunity to name a health care proxy. Politically a revision of the convention would require staying broad enough to allow for cultural flexibility.

Another main issue of workshop was to face questions about the **normative ethical basis of advance directives**. Since the stability of the agreement stated in the Oviedo convention can be questioned and views about what should happen with incompetent patients are culturally diverse, a clarification of common normative-ethical basis is necessary. The group advocated a plurality of legal and ethical principles, which could give advance directives force. Such pluralistic approach could help to accommodate cultural differences in clinical practices.

Extended debates have been also conducted on questions about **practical problems of implementation of advance directives in clinical settings**. The group discussed foremost problems with advance directives, which occur under conditions of limited resources in clinical practice (financial budget, time, health care practitioners' training, consulting for patients and relatives etc.).

The question whether a **trans-national register for advance directives** is required was also a heated point of debate. One group suggested creating a European network of registries on advance directives in order to secure travelling people self-determination rights when becoming ill abroad. Besides a coordination of national registries, policies and norms for guaranteeing respect to privacy would also have to be unified.

3. Assessment of the results, contribution to the future direction of the field.

The first day, dedicated to elaborate the situation of advance directives in the particular countries, was helpful to reach common ground for further discussions. The abstracts and discussions already demonstrated a great lack of research regarding empirical as well as normative issues. Moreover, the workshop discussions and working group sessions demonstrated a tremendous need for future empirical, legal and ethical research on advance directives. Thus one main focus of the workshop was to pinpoint these gaps of knowledge for possible future collaborations

Further research questions

The most prestigious research issues brought up are the following:

Empirical research questions:

- The guiding question for empirical research is: What do we have to know about clinical practice in order to enhance advance directives implementation?
- To improve implementation it would be important to have greater knowledge about attitudes of nurses and physicians towards advance directives.
- As a starting point to see obstacles and barriers for advance directives it would be also useful to investigate attitudes of nurses and physicians towards dying in dignity, patient right to self-determination, paternalism, and refusing treatment of incompetent patients.
- There is almost no data about how clinicians take advance directives into account when making medical decisions.
- Also there is no data about the experience of family members and proxy decision-makers with the implementation of advance directives.
- Study of concordance between patients', relatives', and health care practitioners' preferences.
- What are the obstacles for the use of advance directives in clinical practices (personal, institutional, societal-cultural, legal)?
- Does the socio-economic status play a role whether or not a patient writes an advance directive?
- What are the motives of patients to withhold their advance directives?
- Survey on the content, format and functioning of advance directives in European countries

Normative-ethical research questions:

- What is the normative-ethical basis for advance directives? (e.g. the patient bears the consequences, autonomy, dignity, respect for private life, personal integrity etc.)
- Should the possibility to write an advance directive be limited to *terminal* illness with *irreversible* incompetence? Is there a normative-ethical reason to restrict the scope of advance directives to end-of-life decisions?
- How could the social network-concept be embedded in an approach of advance directives (e.g. by clarifying the role of the family)?
- Medical decision-making processes are based on probabilistic information. How can we implement advance directives under conditions of uncertainty?
- What duties do a physician has when facing a patient decision?
- Circumstances of achieving autonomy have become more complex in European countries because of a highly specialized health care structure. Is this new structure in favour of patient autonomy, and how do advance directives could help in this matter?
- What are “good” advance directives?
- What are potential abuses of advance directives? (e.g. making it mandatory for entering nursing homes)
- Are advance directives ethically required in countries with a more paternalistic clinical practice?
- Advance directives are one way of conceptualizing dying processes and end-of-life-decisions. What are the normative implications of this conceptualization? And what cultural differences do we encounter here?

Legal research questions:

- Do we need a coordinated legal view on advance directives in Europe?
- What are the scope and implications of article 9 of the Oviedo convention? (e.g. who is covered by the article (competent and incompetent persons?))
- Survey on the implementation of article 9 of the Oviedo in countries which ratified the convention.
- Survey on the impact of legal and professional guidelines on advance directives and related issues (end-of-life decisions, patient autonomy)
- Survey in how laws on advance directives are applied and followed in clinical practice of particular countries
- Possible conflict between proxy decision-maker and advance directives
- Creation of laws is one way of changing culture. Should a consensus on advance directives be promoted by law giving (on national or European level), or should

legislation wait until a social-cultural consensus has been developed in a particular society/in Europe?

Further publications and collaborations

The first action of the workshop group was to publish a revised version of the Book of Abstracts as Country Reports, which is on-line available at the following website: <http://www.ethik.uzh.ch/ibme/en/>. The idea was to make the results of the workshop accessible to the scientific community fast and easily. A book publication of the country reports is also planned.

The workshop group expressed interest in publishing the results of the discussions in a scientific journal article. The convenors are currently drafting an article that pinpoints the differences of legal and clinical practices, scope and bindingness of advance directives in various countries. This article will be submitted to one major bioethical journal.

Prior to the workshop one participant from Spain launched together with some colleagues an on-line Collaborative on Advance Directives: <http://www.voluntadesanticipadas.com>. The purpose of the website is to gather information about advance directives all over the world. Further ideas of research collaborations will be explored.

4. Final Programme

Wednesday 18 June 2008

18.00 *Arrival, reception and registration*

Location: Center for Ethics, Zollikerstrasse 115, Zurich

Thursday 19 June 2008

Location: Center for Continuing Education (ZWB), Schaffhauserstrasse 228, Zurich-Oerlikon

08.30-09.00 **Registration**

09.00-09.30 **Welcome Presentation of the European Science Foundation (ESF)**

Joachim Alexandre Ribeiro (ESF Standing Committee for the European Medical Research Councils – EMRC)

Kostas Gouliamos (ESF Standing Committee for the Humanities - SCH)

State of the art

09.30-11.00 **Session 1**

Chair: Susanne Brauer

Lisa Lehmann (USA)

Anne-Marie Slowther (UK)

Pekka Louhiala (Finland)

Per Nortvedt (Norway)

Eimantas Peicius (Lithuania)

11.00-11.30 *Coffee break*

11.30-13.00 **Session 2**

Chair: Susanne Brauer

Julia Inthorn (Austria)

Arnd May (Germany)

Peter Lack & Claude Regamey (Switzerland)

Mette Rurup (Netherlands)

Chris Gastmans (Belgium)

13.00-14.30 *Lunch*

14.30-16.00 **Session 3**

Chair: Roberto Andorno

Fabrizio Turoldo (Italy)

Jean-René Binet (France)

João Loureiro (Portugal)

José Seoane & Pablo Simon (Spain)

Takis Vidalis (Greece)

16.00-16.30 *Coffee break*

16.30-18.00 **Session 4**

Chair: Nikola Biller-Andorno

Violeta Besirevic (Serbia)

Katarina Glasova (Slovak Republic)

Assya Pascalev (Bulgaria)

Tolga Guven (Turkey)

Judit Sandor (Hungary)

18.00-18.30 **Organisational Matters**

19.30 *Dinner (Restaurant Linde Oberstrass, Universitätsstrasse 91, 8006 Zurich)*

Friday 20 June 2008

Location: Center for Continuing Education (ZWB), Schaffhauserstrasse 228, Zurich-Oerlikon

Working Groups

09.00-09.30 **Introduction**

09.30-10.30 **Working Groups**

10.30-11.00 *Coffee break*

11.00-13:00 **Working Groups (continued)**

13.00-14.30 *Lunch*

14.30-16.00 **Working groups (continued)**

16.00-16.30 *Coffee break*

16.30-18.00 **Working Groups (continued)**

18.00-18.30 **Organisational Matters**

19.30 *Dinner (Restaurant Il Postino, Schaffhauserstrasse 188, 8057 Zurich)*
– at own cost

Saturday 21 June 2008

Location: Center for Continuing Education (ZWB), Schaffhauserstrasse 228, Zurich-Oerlikon

Results & Future Collaborations

09.00-09.30 **Introduction**

09.30-11.00 **Results of Working Group I**
Chair: Susanne Brauer

11.00-11.30 *Coffee break*

11.30-13.00 **Results of Working Group II**
Chair: Susanne Brauer

13.00-14.30 *Lunch*

14.30-16.00 **Results of Working Group III**
Chair: Nikola Biller-Andorno

16.00-16.30 *Coffee break*

16.30-18.00 **Concluding discussion & Future collaborations**
Chair: Nikola Biller-Andorno

18.00-18.30 **Organisational Matters**

5. Statistical information

Age :

between 30-35 years:	6
between 36-40 years:	6
between 41-45 years:	7
between 46-50 years:	3
between 51-55 years:	2
between 56-60 years:	1
between 61-65 years:	
between 66-70 years:	1

Countries : Austria (1), Belgium(1), Bulgaria(1), Finland (1), France (1), Germany(1), Greece (1), Hungary (1), Italy (1), Lithuania (1), Netherlands (1), Norway (1), Portugal (1), Serbia (1), Slovakia (1), Spain (2), Switzerland (6), Turkey (1), UK (1), USA (1)

Gender : 15 male, and 11 female participants

6. Final List of participants

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