Towards a European understanding of advance decision-making: a comparative, interdisciplinary approach

Seminar 1: Advance decision-making – the context, the promise and the pitfalls.
Programme

• Programme:-
• 09.30 Registration and coffee
• 09.30 Welcome, opening remarks and introductions
• 09.30 Jean McHale “Advance decisions and the MCA 2005: Just where did it all go wrong?”
• 09.30 Dianne Gove “Practical and ethical issues related to the use of advance directives by people with dementia”
• Followed by time for questions
• 12.10 Lunch
• 13.30 William Molloy “Let Me Decide: an update on recent research”
• 14.15 Coffee
• 14.45 Celia Kitzinger & Sue Wilkinson “Writing an Advance Decision: (How) Can We Facilitate the Process?”
• 15.45 Closing remarks
• 16.00 Close
Professor Jacqueline Atkinson

Formerly Professor of Mental Health Policy at the University of Glasgow she has carried out research in the area of mental health legislation for more than 20 years. She was advisor to the Scottish Parliament in respect of the Mental Health (Care and Treatment) (Scotland) Act. She published the first book on Advance Directives in Mental Health in 2007.
Professor Peter Bartlett

• In his own words:

• Peter Bartlett is Nottinghamshire Healthcare NHS Trust Professor of Mental Health Law in the School of Law and Institute of Mental Health at the University of Nottingham. He was specialist advisor to the House of Lords Post-Legislative Scrutiny Committee on the Mental Capacity Act 2005. With colleagues in Nottingham, he has recently completed a study of the use of advance planning and decision-making by people with bipolar disorder, the results of which will be published later this year in the *Journal of Social Welfare and Family Law*. Professor Bartlett is today sprinting towards a deadline imposed by a funder, and deeply regrets not being in Leeds at this seminar.
Factors Associated with Initiation of Advance Care Planning in Dementia: A Systematic Review

Jenny T. van der Steena,*, Mirjam C. van Soest-Poortvlieta, Meertje Hallie-Heiermana,1, Bregje D. Onwuteaka-Philipsenb, Luc Deliensb,c, Marike E. de Boera, Lieve Van den Blockc, Nicole van Udenc,2, Cees M.P.M. Hertogha and Henrica C.W. de Veted

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Louise Bramley
PhD Student and Staff Nurse
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Sharon Burton

• General Medical Council (GMC)
• Head of Policy, Standards and Ethics
Professor Martin Eisemann, PhD
Dept of Psychology, Faculty of Health Sciences
UiT The Arctic University of Norway in Tromsø

Related publications to “advance decision-making”:
• Attitudes towards self-determination in health care -- a general population survey in northern Sweden.
• Relationships between various attitudes towards self-determination in health care with special reference to an advance directive
• Factors influencing Swedish doctors’ decision-making in the care of incompetent elderly patients.
• Decision making in the incompetent elderly: "The Daughter from California syndrome".
• Variability in physicians’ decisions on caring for chronically ill elderly patients: an international study.
• Factors affecting physicians’ decisions on caring for an incompetent elderly patient: an international study.
• Decisions and attitudes of nurses caring for severely ill elderly patients: a culture-comparing study
• Physicians’ decision-making in incompetent elderly patients: a comparative study between Austria, Germany (East, West), and Sweden.
• Decisions and attitudes in treatment of incompetent, chronically ill, aged patients. A comparison between nurses and physicians: why does no one ask the nurse?
• Decisions and attitudes of nurses in the care of chronically ill elderly patients
• Attitudinal patterns determining decision-making in the treatment of the elderly: a comparison between physicians and nurses in Germany and Sweden.
• Physicians’ attitude in the treatment of incompetent patients. Comparison between East and West Germany
• The compliance of doctors and nurses with do-not-resuscitate orders in Germany and Sweden
• Doctors' authoritarianism in end-of-life treatment decisions. A comparison between Russia, Sweden and Germany
• Attitudinal patterns determining decision-making in severely ill elderly patients: a cross-cultural comparison between nurses from Sweden and Germany.
• Personality characteristics of physicians and end-of-life decisions in Russia.
• Decision-making in the treatment of elderly people: a cross-cultural comparison between Swedish and German physicians and nurses.
• Doctors' attitudes and end-of-life decisions in the elderly: a comparative study between Sweden, Germany and Russia.
• A new instrument to describe indicators of well-being in old-old patients with severe dementia--the Vienna List
Topics

- End-of-life care ethics
- Dementia care ethics
- Care ethics

Prof Dr. Chris Gastmans
KU Leuven, Faculty of Medicine
Centre for Biomedical Ethics and Law
www.cbmer.be
Alzheimer Europe
Position Paper

Advance Directive
(living will)
Advance Decision Directive?

Tamara Hervey (Tammy)
Jean Monnet Professor of EU Law
School of Law, University of Sheffield
Samantha Halliday, Associate Professor in Law, University of Leeds, UK

Research interests: comparative medical ethics & the law at the beginning and end of life.

Selected publications:


S.Halliday@leeds.ac.uk
Gillian Lewando Hundt
Professor of Social Sciences in Health

Medical Anthropologist/Sociologist
Research Interests in the Area of Advanced Decision Making

• Views of People and Carers living with life limiting conditions on Assisted Dying – eg MND
• Models of compassionate communities
• Decision making of patients relating to end of life care
• Developing theatre from research
UNIVERSITY OF SALERNO - SCHOOL OF LAW

Prof. Vitulia IVONE
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– Chairman of the Scientific Board of the Fondazione Scuola Medica Salernitana (http://fondazioneescuolamedicasalernitana.org/)
– Founding Member of the Advisory Board of the Observatory on Human Rights: Bioethics, Health, Environment
– Member of the research group of the Italo-German VIGONI Programme 2011-2012: Legal and ethical questions raised by end-of-life decision-making in Germany and Italy: a comparative and international law perspective

Research interests: right to health and bioethical/legal issues concerning the beginning and end of life, informed consent, medically assisted procreation, pre-implantation genetic tests, advance directives and living wills, palliative care, dignity and human rights at the end of life, medical responsibility
Kirstin Jalink
MD (GP and elderly care)
PhD student Advance Care Planning
VU medical center Amsterdam, The Netherlands

No thank you!

Think before you start…
Celia Kitzinger, Sociology, University of York

healthtalk.org + ‘coma’

Guardian “Impact Award” (Runner up)
Arnd T. May PhD  
Ethicist in the field of clinical ethics  
consultation  
Centre of Applied Ethics, Recklinghausen GER

- Interpretation of an Advance Directive to provide treatment in accordance to patients wishes
Prof. Stefania NEGR

Associate Professor of International Law
Lecturer of International Human Rights Law
email: snegri@unisa.it
http://www.unisa.it/docenti/stefanianegri/en/index
http://salerno.academia.edu/StefaniaNegri

– Founder and Director of the Observatory on Human Rights: Bioethics, Health, Environment (www.odubsa.unisa.it - odubsa@unisa.it)
– Member of the Scientific Board of the Fondazione Scuola Medica Salernitana
– Director of the Italo-German VIGONI Programme 2011-2012: Legal and ethical questions raised by end-of-life decision-making in Germany and Italy: a comparative and international law perspective

Research interests: human rights in international and European law, right to health, informed consent, advance directives in European perspective, bioethical/legal issues concerning the end of life, euthanasia and assisted suicide, palliative care, global public health, food safety
Professor Jean McHale

Professor Willie Molloy
Alex Louise Pearl
2nd Year PhD student based in School of Law
A.Pearl@leeds.ac.uk
Andrea Prescott, Court of Protection and Public Law Solicitor, Cartwright King
Motivation – like everybody, I am a potentially aggrieved party, I gained some experience with medical paternalism in more than 25 years clinical practice in a psychiatric university hospital, and I would like to have a say when my time comes.

One of the first persons who studied doctors’ and nurses’ attitudes towards advance directives in end-of-life decisions in Germany already from 1995 in collaboration with Prof. Dr. Martin Eisemann (Umeå/Tromsø) and Prof. Dr. Willie Molloy (Hamilton/Cork) in cross-cultural comparisons (Sweden, Russia, Austria, Germany).

**selected publications:**


ACP in dementia in UK

Newcastle: Louise Robinson, Cath Exley, Julian Hughes

Research (NIHR funded)

Effectiveness? (Robinson et al 2010)

Use and feasibility in practice? (Robinson 2012)

Messages for practice **Living for the present**

• No one’s responsibility
• Best interests decision making trump ACP
• Levels of acceptability
  – LPA: acceptable to all stakeholders
  – DNH/DNR orders - **AVOID ADRT**
Kevin de Sabbata

• PhD student, University of Leeds.
Dr Maria Stuttaford

• Social scientist working across disciplines including law and public health
• Health as a human right, focusing on:
  • how civil society organisations (CSOs) use a human rights approach to tackle health inequalities
  • the right to health in the context of plural health seeking behaviour
  • the right to health and participation
• Honorary Research Fellow, Cardiff University, UK
• Honorary Senior Lecturer, University of Cape Town, SA
• Associate Fellow, University of Warwick, UK
Professor Sue Wilkinson

• Professor of feminist & Health studies, University of Loughborough.

• Sue is a Professor in the Department of Social Sciences at Loughborough University. She has worked with Compassion in Dying and Dementia UK to evaluate their telephone helpline services, and is a befriender for Friends at the End (FATE).