LEGAL AND ETHICAL ISSUES SURROUNDING RISK PREDICTION OF PERSONS WITH DEMENTIA

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INTRODUCTION

• Thanks to the organizers and funders;
• About my self;
• About this presentation:
  • What is it not: no discussion re the ability or accuracy of prediction;
  • What is it not: no answers;
  • What it is: What are the questions?
  • What it is: The “Double Edge Sword” characteristics of Dementia Prediction
• The difference between “ethical” and “legal” dilemmas in the context of this presentation
• Some general background regarding the Human Rights of Older Persons – in general; and the Human Rights of Persons with Dementia – in specific;
THE DARK SIDE OF DEMENTIA PREDICTION

• “Alzheimerism”: the stigma around dementia
• Discrimination:
  • Health insurance & other types of insurances (e.g. long term care; disability; life)
  • Exclusion in cases of scarce resources;
  • Labor force and employment;
  • Personal relationships;
  • Personal Fraud and abuse;
  • Various “privileges” (e.g. driving? Voting?)
• “Self-Alzheimerism”: the internalization of social expectations
  • Depression or determinism;
  • Denial and self harm;
• Social pressure “to know your future”: loss of choice
• Social pressure to “behave properly” (e.g. participate in experiments? Not marry?)
• Questioning one’s autonomy…..
• So, what are the key legal issues?
AUTONOMY

• Autonomy in general
• Freedom, liberty, and choice: consent
  • Who and how decides to have “dementia prediction” tests? (e.g. informed consent)
  • Can one be “required” to have such tests (e.g. can this be required as part of a job interview?)
• Who and how decides to let a person know about “dementia prediction” outcomes? What is the ethics of “disclosing” such a diagnosis?
• Has a person the right to “destroy” dementia prediction data?
PRIVACY, SECRECY & CONFIDENTIALITY

• Once there is a determination regarding the Dementia Prediction exam:
• Who is the legal “owner” of this data and who “controls” it?
• Who has the legal right to access it? Can public bodies access it? E.g. police? The military? The driving authority?
• Can private bodies access it? E.g. health insurance companies? Life insurance companies? Private employers?
• Can family members access it?
• What should be the grounds to justify breaching privacy and confidentiality?
• In general: a legal lacuna
• In general: the need for specific legal regulation and legislation;
• There are legal some “reference points” (e.g. Genetic Testing Legislation);
• In specific:
  • Should there be legal regulation for early detection/early prediction tests for dementia? (e.g. do you need a “license”? What are the requirements? Who and how decides?)
  • Does or should the early prediction of dementia - change the legal “status” of a person? (e.g. entitlement to disability rights? Legal capacity in contract law? Tort liability regarding damage for 3rd parties?)
  • What are the “human rights” of people in the context of dementia prediction?
So Where Do We Go From Here?

- My starting point was: unfortunately, I don’t have the answers;
- Moreover, there are not “single & simple” answers;
- However, I do have a few insights:
  1. It is clear that it is time not only to discuss the ethical and legal implications of dementia prediction, but also actually start “doing” something about it (e.g. legislation; regulations, etc.)
  2. It is clear that dementia prediction raises not only numerous ethical and legal questions, but that they raise real and significant dilemmas, which if left unregulated – may cause serious harm;
  3. Learning from past experiences, e.g. Genetic Testing – it is clear that the basic approach needs to be a human rights approach: i.e. the person is in the center: autonomy, freedom of choice, privacy, equality and prevention of discrimination should be at the core of any legal and ethical regulation of this field.
  4. In this spirit – the voice of people with dementia should be heard and be taken into account in any regulatory process;
- Finally, in light of the growing intersectionality of ableism, ageism, and “Alzheimerism” – it is crucial not to believe that we can simply wait – the potential dangers are too high.
Thank you very much and my apologies for not staying for the discussion.

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