



LEGAL AND ETHICAL ISSUES SURROUNDING RISK PREDICTION OF PERSONS WITH DEMENTIA

Prof. Israel Issi Doron

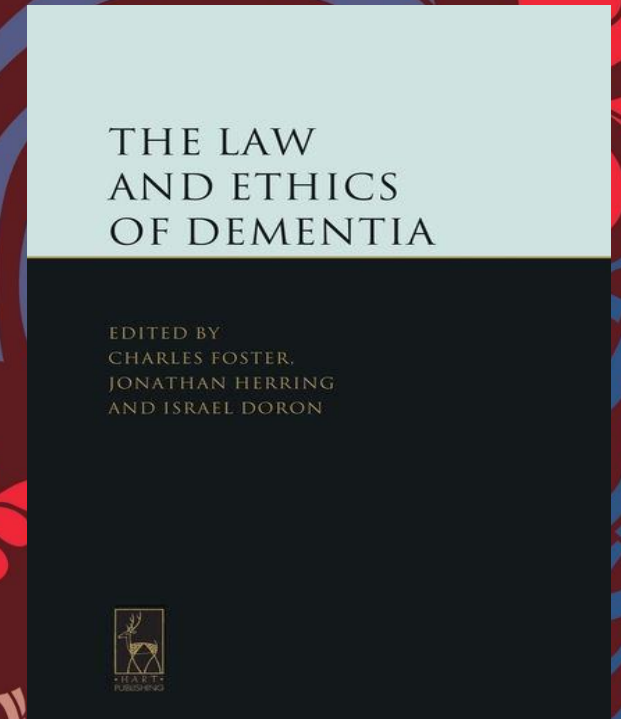
CRSA – Center for Research & Study of Ageing
Department of Gerontology, University of Haifa
Haifa, Israel 31905; idoron@univ.Haifa.ac.il

CRSA

המרכז לחקר ולימוד הזיקנה
The Center for Research & Study of Ageing
مركز تعليم وبحث علم الشيخوخه

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?

BROADER LEGAL POLICIES

- 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

- Prof. Israel Issi Doron
- idoron@univ.Haifa.ac.il

