

Ethical challenges of healthcare and cancer policy On solidarity and autonomy

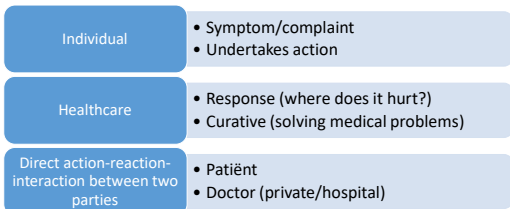
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Where do we come from

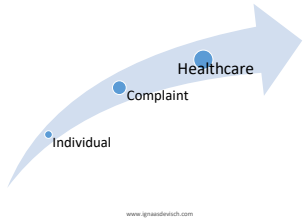
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Curative healthcare

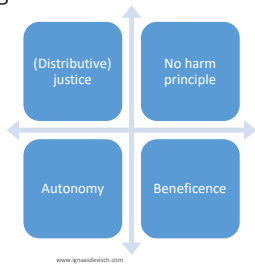


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Curative healthcare



Ethical challenges



Solidarity

• Right to healthcare for everyone but no obligation to take care of your health (not as a condition)
• Solidarity is based on ignorance: inability to predict your future health

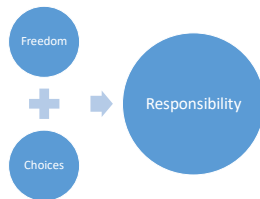
Because no one knows in advance what will happen in the future and everything can always happen to anyone, we are solidary with each other

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Where are we heading towards

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Evolution in HC



- Existential range expands because we can intervene more
- The more we know, the harder to escape responsibility

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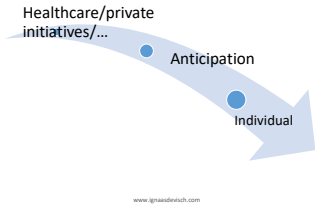
Prevention

- Possibility to discover without/before symptoms occur
- We know more and we anticipate more
- The better we anticipate, the more we (may) prevent harm from happening
- Therefore: screenings, research, biobanking, ...

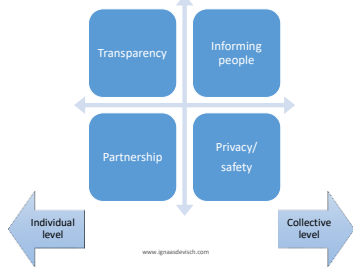
Morabia A, Zhang, Postgrad Med J 2004;80:463-469 History of medical screening: from concepts to action.

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Initiative is no longer solely individual



Ethical challenges (on top of existing ones)



Solidarity is shifting

- We can share the possible profits (datasharing) but what about the losses?
- Will we still be solidary if we know each individual's risks in advance?
- Do we have the right to be forgotten? (privacy)
- Will people with cured cancer be discriminated? (insurance, mortgage)

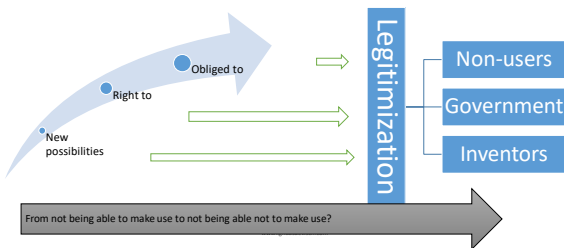
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Right not to know?

- New tests and screenings
- What about those who don't want to know?
- Is not knowing= not taking care?
- E.g. screening (if you can know it, do you have to?)
- New technologies come with new obligations (moral parenthood etc)

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Evolution ethical debates on medical technology/innovations e.g. NIP test



Challenges

- How to safeguard autonomy? (autonomy presupposes informed choice between worthwhile options)
- Shall we put efforts on informing and engaging people in becoming partners or in punishing them for not knowing?
- Not judging people for not making use of things without informing them properly
- Prevent health care system from evolving towards 'the freedom to make the right choices'

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From autonomy to partnership

Thinking collectively to become personal

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Partnership in care?

- Daniel Callahan:
 'bioethics has brought patients into a full partnership with physicians in their medical care'
(1984, *Autonomy, a moral good, not a moral obsession*):
- Patients as active partners in clinical research (Blasimme and Vayena, 2016)
- Partnership?

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Evolution in healthcare

- Declaration of Alma-Ata, WHO, 1978, USSR: *"The people have the right and duty to participate individually and collectively in the planning and **implementation** of their health care"*
- BMJ, 2014: 'Listen to patients first': *"transformation from an approach that took an organisational perspective to one that now starts with "what patients really want to know."*

Important questions

- How to increase the awareness of what you can do as an individual?
- How to implement partnership?
- How to offer meaningful options to people to become members in partnership?
- How to leave the level of engagement to the individual?

We need a new understanding of autonomy

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Core current principle of autonomy

- Being adequately informed
- Capacity to process information
- Absence of coercion or manipulation
- My freedom begins where the freedom of the other ends*

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What kind of autonomy do we need in the future?

- To determine the course of one's life
- Absence of coercion
- A meaningful range of worthwhile options to choose from
- My freedom begins where the freedom of the other begins*

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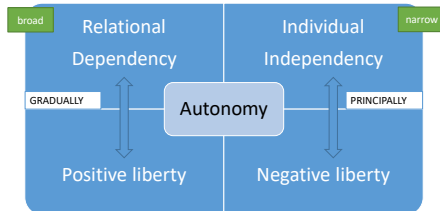
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When autonomy meets freedom *



* Isaiah Berlin, *Two concepts of liberty*
