The Active Patient Between Citizen and User

New Roles for Patients in late Welfare Society

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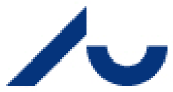
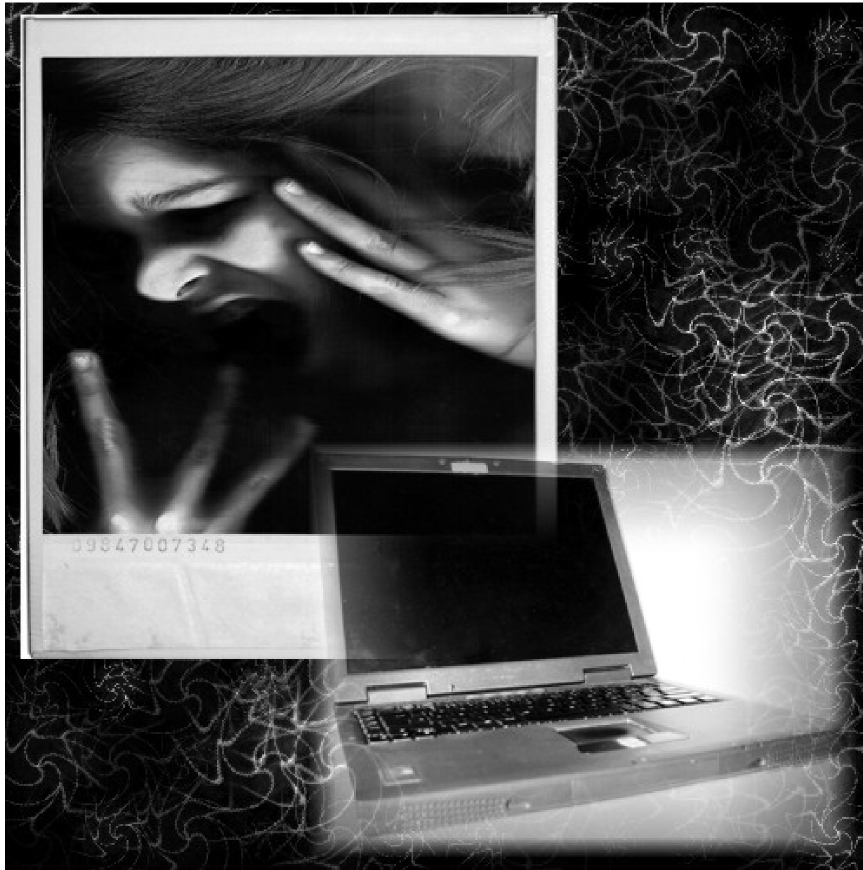


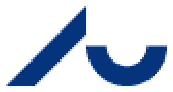
Headlines

- The welfare state patients
- Individualisation
- The self-managing patient
- The self-responsible citizen

Both-And



Slow enthusiasm



Shifting patient roles

- With 19th century medical science and technology a historical shift happens in communication:

a) Direct communication between patient and doctor

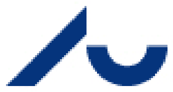
b) Direct communication between patient’s body and doctor through examination, e.g. palpation or direct auscultation

c) Indirect communication between patient’s body and doctor through technological mediation

- From subjective experience of illness to objective knowledge about disease

Disease and body at the center

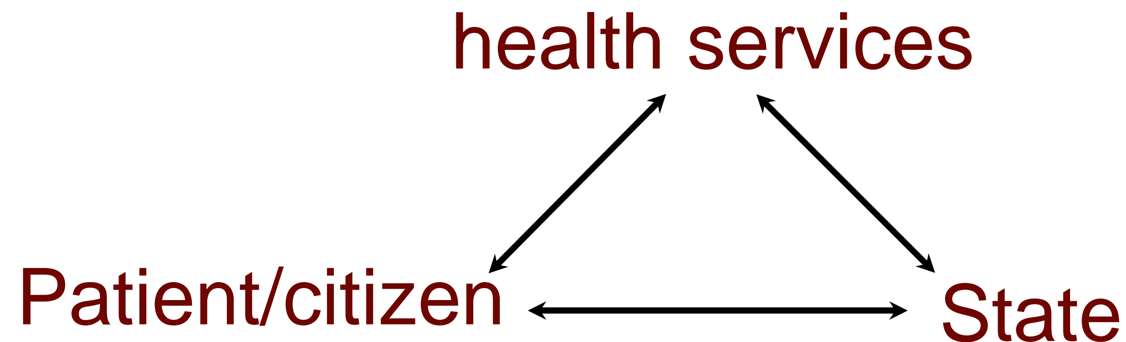
- With new technology and medical art turning into a science, medicine came to be about diseases and the biological body, more than about the whole person
- Patient knowledge is particular og subjective; medical kowledge is general and objective
- Assymetric relationship between patient and health professionals; compliance regimes are evident
- This assymetric relationship dominates the conception of patients in most part of 20th century



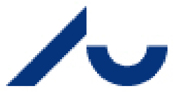
The patient in the state

- Relations between state, health sevices and patients in the welfare state have been transformed in recent decades
- Danmark has, since the 50s been characterised by welfare state regulations of public health services via a comprehensive public service system
- The basic players:
  - Citizens/patients: general and specific expectations
  - The state: the paying and providing party
  - The health services: the executing party

The welfare state and its patients

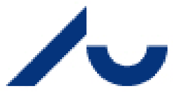


- The patient is passive - submitted to institutionel control of events
- The citizen is active - votes at elections
- The health services dominates - defines patients' roles through diagnoses and inspections
- The state regulates - makes laws and regulations



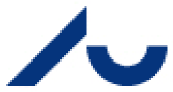
The common goods

- In the classical welfare state it is the state and health professionals who are committed to define and determine:
  - The needs of citizens
  - The extend of public services
  - The just, equal distribution of services and goods
- Paternalistic role of the state and the professionels, but for the common good



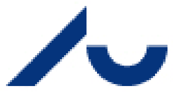
Transitional times

- The welfare state today is exposed to several kinds of pressure:
  - economic
  - demographic
  - ideological-political
  - individualistic
- Significant displacements in relations between state and citizen



The individual goods

- Public 'welfare' can not be taken for granted today
- Growing number of requirement on the patient
- The patient also makes more demands on her/himself
  - more choices
  - higher level of information
  - new kinds of treatment
- New patient roles are emerging placing the individual patient in a central *self-managing* position



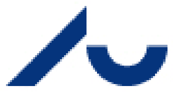
Individualisation

- Self-management has become a desire, a trend, a norm
- It expresses the wish of citizens to gain more *independent, individual choices*
- Individualisation as a new guiding ideal of ‘the good life’ away from state control
- So what is individualisation?
- Two theoretical meanings:
  - neoliberal
  - social science

- Neoliberal thinking presupposes the *self-ruling* human being
- No needs for outer control, each individual is able to control his own life solely based on inner, personal ressources
- Sovereign entrepreneur of his own life
- The basic duty of the (minimal)state is to fascilitate the efforts of the individual

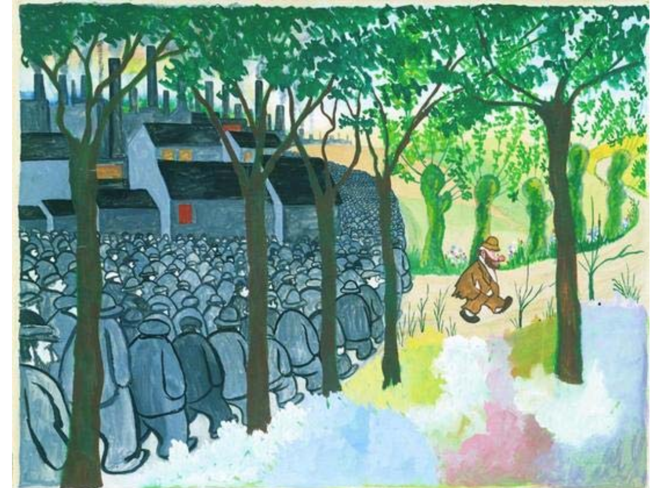
B: The socialised individual

- The single person’s individualisation can not be separated from his/her socialisation
- Sociological core idea in e.g. Marx, Weber, Durkheim, Foucault, Habermas, Beck
- Individualisation is a *product of* complex, contingent and well-developed socialisation
  - a structural, profound feature of socialisation
  - does not work against, but rather nurtures socialisation



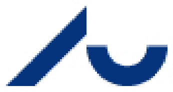
ISO individuality

- Self-realisation happens based on common ideals about e.g. the grand world journey; the best dress code; the exotic taste in music; the individual choice of welfare services, etc.
- Each person wants to be *recognised* in her choices by family, friends and society
- *Individualisation is a common social norm*



The tramp as the (a-liberal) exception

- Currently a growing marketization and neo-liberalisation of health services:
    - free choice of hospital and services, rate managagement, contract management, new providers of health services
    - business-determined leadership
- Places the patient at the center as a demanding player:
    - is equipped with specific rights on the market
    - expects the providers of health services to create a transparent, competive supply of services



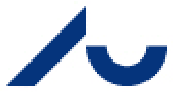
Patient as a user

- The patient has become a ‘user’ of health care
- A user? - An agent, who uses a product, or receives a service made available by other instances or agents
- In computer-lingua: an *end-user* of pre-defined products and services, normally without particular technical skills or insights

- A wide-ranging concept:
  - End-users:
    - Financial buyers
    - lead users
    - specialists
    - Passive buyers
  - Users in the distribution chain
  - Internal users in the producing company

Non-users

- Over-rule the 'I-methodology' in design!
- Non-users as a category - can not just be reducered to 'drop-outs' (Sally Wyatt):
  - resisters - will not
  - rejecters - will no more
  - excluded - can not
  - expelled - can no more



The neoliberal user

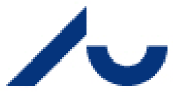
- Problems and solutions are not solely defined by health professionals anymore, rather by their ‘users’, who know best with regard to own needs and demands
- Users both have a duty and a right to be listened to

- Curently comprehensive attempts to digitize basic health services:
  - EHR, social networks, pervasive healthcare-technologies, telemedicine, welfare technologies
- The expectation is to sustain and improve task requirements and services in health care
- Particular patient groups in their own home are to be involved in the production of health services:
  - self-monitorering and self-diagnosticering
  - technical evaluation and support

Current disease patterns

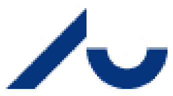
- Current political motivations to displace or transform the state's responsibilities in public healthcare:
  - changing demography; more elderly people, fewer productive people in the work force, fewer tax payers
  - altered disease patterns linked with mal-nutrition, tobacco and alcohol
  - Increased number of patients with chronic diseases: heart diseases, cancer, chronic respiratory diseases (copd), diabetes, etc. - 80% of health spenditure goes to chronic diseases
- Patients with chronic diseases are generally (most of the time) in less need of intensive treatment and care
- More pressure on primary healthcare for new solutions

- Current activities to move power from health professionals to patient and relatives; away from compliance regimes
- Patient schools established to strengthen empowerment in patients with chronic diseases
- Patients must learn to handle their conditions in their own environment based on own values and needs
- Empowerment is ment to establish this foundation



Telecare/telemedicine

- Treatment and care of patients at a distance
- Lack of specialists in the future; longer physical distances to treatment and hospitals
- Possibility of ‘second opinion’ from a specialist overcoming distance
- Expected halving of admittances to hospitals, as well as improvement of treatment and care
- Hospitalising patients in their own home



The Patient Briefcase

Satellite connection

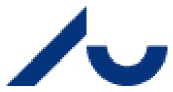
Computer at hospital

Patient briefcase

Internet

- Patients get the briefcase within 24 hours days after discharge from hospital for 7 days
- Daily contact with specialist nurse via system (one-button interface)
- Self-measurement of blood saturation, spirometry (peak flow & volume), pulse
- Instructions and evaluation from nurse
- The procedure prevent undue re-admittances
- Succesful test so far: general satisfaction

Project manager Anne Sorknaes, phd student and specialist nurse



Self-fare technology?

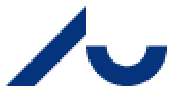
- The state, citizens and producers all have demands regarding development and use of individualised systems in the public sector
- The conception of technology becomes significant: is it a tool, management, empowerment, control?

The citizen-patient at the center

- Self-managing patients with more rights and duties - modern citizen ideal
- Have direct *influence* on offers of health services and choices, and have direct acces to own data in health records
- Is committed to an active role in her/his own (or family memebers') disease process

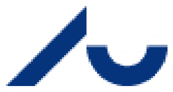
The patient as self-managing employee?

- Is committed to an active, but disciplined kind of conduct, regulated by control systems and management technologies
- Voluntary submission to rules and regulations - at a distance - as part of the agreed contractual relationship with the health services
- Self-management is, at present, a general norm:
  - “Self-management competency is the ability and will to make decisions about one’s own work with regard to method, planning and implementation as contribution to the realization of the company’s ends and values.” ([*The Danish*] *National Competency Account* 2005)



Is the citizen replacing the patient?

- Hypothesis: It is the healthy patient/the active citizen/the proficient user, who makes demands and is able to be responsible for her/his self-managed treatment and care
- The sick patient may not be able to take on this self-responsibility
- Hall & Salmon: Patient empowerment is only for healthy patients, who will and can take control. What happens when they get sick?



Summa summarum

- Individuel self-management supports health political ends to save money and other public ressources of treatment and care, and to liberate patients from passivity and compliance regimes
- Technological health services may offer satisfactory solutions to individual patients through empowerment regimes
- Such solutions, however, may also undermine, or blur public responsibilities, and citizens' rights to health services: "Look, these patients obviously want to manage their own healthcare path. So we should not stand in their way!
- Suggestion: explore differentiated notions of patients and relate closely to sociotechnical studies of human-technology relations

Thank you!