What is a diagnosis: is it crystal clear with an obligate treatment that can be measured and benchmarked? How do we prevent overdiagnosis and –treatment?

GP, MD Seija Eskelinen
Chair of The Finnish Association for General Practice
Helsingör 2018



#### What is a diagnosis: is it crystal clear?

- Gr. dia between/by, gnosis knowledge
- refers both to the process of identifying a disease and also to the conclusion of the process
- the universe of diagnoses are expanding with the process of medicalisation (Zola 1972)
- medical metaphores inform teories of society: "sick economies", "healthy societies"
- Louhiala P. What do diagnoses mean and does it matter? In: Ahlzen R, Evans HME, Puustinen R, Louhiala P (eds.). The Medical Humanities Companion Volume Two: Diagnosis. Oxford: Radcliffe 2010

#### What is a diagnosis: is it crystal clear?

- "Each civilization defines its own diseases" (Illich)
- patients suffer from "illnesses" and doctors diagnose and treat "diseases"
- no universally accepted criteria for establishing disease
- "abnormalities in the function and structure of body systems"
- diagnoses come and go -many factors outside medicine have an influence on their popularity
- labels also change, not the phenomena people experience
- no more hysterics or neurastenics ---fibromyalgia,CFS
- is the diagnosis somehow helpful for the patient?

### Typology of diagnoses

- diagnoses are defined by setting an arbitrary point on a continuum e.g.
  - high blood pressure, high cholesterol, diabetes
- symptom diagnosis constipation
- anatomically defined diagnosis middle ear infection
- causal definition of diagnosis- pneumococcal pneumonia
- syndromes agreed number of criteria
- diagnoses of exclusion e.g. irritable bowel syndrome

### Is it crystal clear - with an obligate treatment?

Major consequences in people's lives:

- social e.g. alcoholism
- economic e.g. valid cause for early retirement or the reason for denying employment or insurance
- cultural e.g. homosexuality: a sin a crime a disease- normal variation of sexual behaviour
- disease as a condition for which individuals do not bear primary responsibility—sufferer is at least to some extent a victim
- the individual is then responsible for adhering to treatment regimens in order to maintain social productivity

### Diagnosis may also create many problems

- It may allow the authorities to lock you up or invade your body.
- You may be denied insurance, a mortgage, and employment.
- You are forever labelled. You are a victim.
- You are not just a person but an asthmatic, a schizophrenic, a leper, an epileptic.
- Some diseases carry an inescapable stigma, which may create many more problems than the condition itself.
- Worst of all, the diagnosis of a disease may lead you to regard yourself as forever flawed and incapable of "rising above" your problem.

# What is a disease? Perspectives of the public, health professionals, and legislators in the Finnish Disease (FIND) Survey



#### Kari A O Tikkinen, Janne S Leinonen, Gordon H Guyatt, Shanil Ebrahim, Teppo L N Järvinen



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Preventing Overdiagnosis Conference 10-12 September, 2013, Dartmouth College, Hanover, New Hampshire, United States

#### **FIND survey Background**

- Doctors considered more non-infectious conditions to be diseases than laypeople<sup>1</sup>
- A survey of the general public, doctors, nurses and parliament members (between June and December 2010 in Finland):
  - to determine the extent to which they considered 60 states of being to be diseases
  - to determine the attitudes towards using public funds for their management

#### **Characteristics of the FIND Survey participants**

	Laypeople	Doctors	Nurses	Parliament members
N	1517	741	966	56
% of females	57	62	97	36
Age (yrs)	%	%	%	%
18-35	22	21	24	4
36-55	36	55	54	46
56-75	42	23	21	50

#### **Characteristics of the FIND Survey participants**

Laypeople		Doctors		Nurses		Parliament members		
Employment (%)		Primary occupation (%)		Employment sector (%)		Political party (%)		
Employed	58	Hospital	45	Public sector	77	Centre Party	25	
Student	6	Health centre	22	Private employer	13	Left Alliance	11	
Unemployed	7	Occupational health care	9	Self-employed	2	Coalition Party	23	
Retired	28	Private clinic	10	Unemployed	3	Social Democratic Party	23	
		Other	14			Other parties	18	

ATTENTION: This is an <u>opinion poll</u> to clarify the concept of disease. The purpose <u>is</u>
<a href="mailto:not">not</a> to find out whether you have any of the states of being/diseases below.

INSTRUCTIONS FOR FILLING OUT THE FORM: Please circle a number 1-5 that best describes your <u>opinion</u> (in both claims A and B).

- 1 = Strongly disagree
- 2 = Disagree to some extent
- 3 = Neither disagree nor agree
- 4 = Agree to some extent
- 5 = Strongly agree

	CLAIM A					
	"[This st	ate of	being	g] is a	d isease"	,
	Strongly disagree				Strongly agree	d
[Myocardial infarction]	1	2	3	4	5	
[Chronic fatigue syndrome]	1	2	3	4	5	
[Baldness]	1	2	3	4	5	
[Absence of sexual desire]	1	2	3	4	5	
[Alcoholism]	1	2	3	4	5	
[Premenstrual syndrome, PMS]	1	2	3	4	5	
[Panic disorder]	1	2	3	4	5	
[Anorexia]	1	2	3	4	5	
[Grief]	1	2	3	4	5	
[Deafness]	1	2	3	4	5	
[Erectile dysfunction]	1	2	3	4	5	
[Motivational deficiency disorder]	1	2	3	4	5	
[Osteoporosis]	1	2	3	4	5	
[Gambling addiction]	1	2	3	4	5	
[Tension headache]	1	2	3	4	5	
[Work exhaustion, burnout]	1	2	3	4	5	
	Strongly disagree				Strongly agree	S

FIND Survey

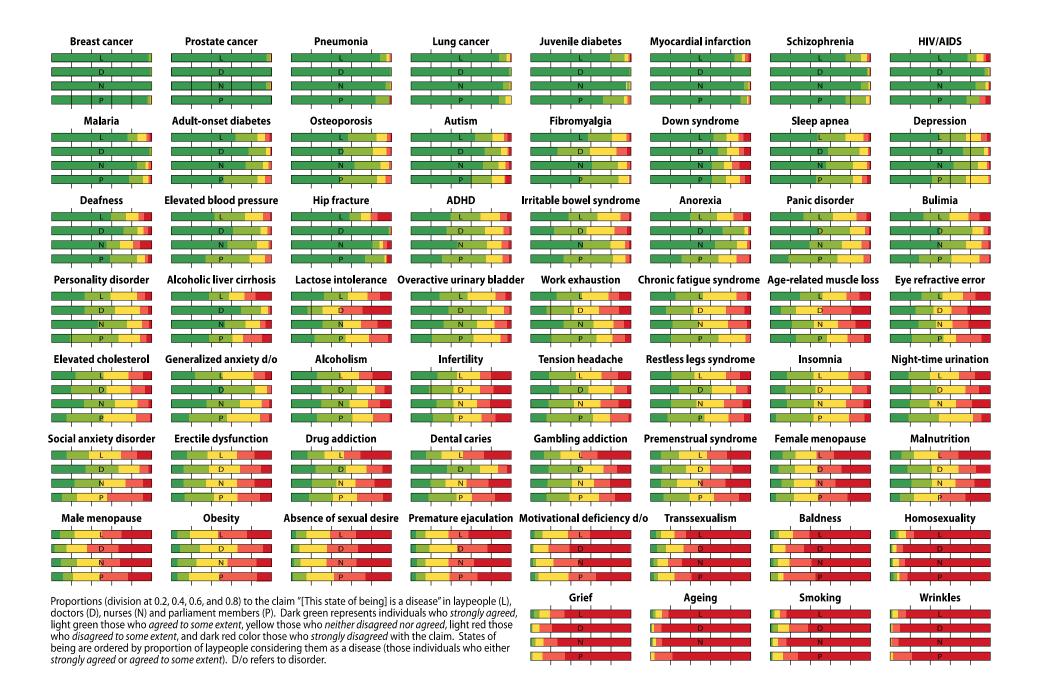
		C	LAIM	A		
	"[This st	ate of	f being	g] is a	d isease"	" tre
	Strongly disagree				Strongly agree	St di
[HIV/AIDS]	1	2	3	4	5	
[Infertility]	1	2	3	4	5	
[Attention-deficit hyper- activity disorder, ADHD]	1	2	3	4	5	
[Prostate cancer]	1	2	3	4	5	
[Pneumonia]	1	2	3	4	5	
[Insomnia]	1	2	3	4	5	
[Obesity]	1	2	3	4	5	
[Drug addiction]	1	2	3	4	5	
[Male menopause]	1	2	3	4	5	
[Ageing]	1	2	3	4	5	
[Transsexualism]	1	2	3	4	5	
[Alcoholic liver cirrhosis]	1	2	3	4	5	
[Schizophrenia]	1	2	3	4	5	
[Restless legs syndrome]	1	2	3	4	5	
[Age-related muscle loss, sarcopenia]	1	2	3	4	5	
[Adult-onset diabetes]	1	2	3	4	5	
[Smoking]	1	2	3	4	5	
[Autism]	1	2	3	4	5	
[Night-time urination]	1	2	3	4	5	
[Binge eating, bulimia]	1	2	3	4	5	
[Generalized anxiety disorder]	1	2	3	4	5	
[Sleep apnea, pauses in breathing during sleep]	1	2	3	4	5	
	Strongly disagree				Strongly agree	St di

FIND Survey

CLAIM B
"[This state of being] should be
treated withpublicex rvenu e"

	CLAIM A "[This state of being] is a disease"			CLAIM B						
				"[This state of being] streated with public ex				venu e"		
	Strongly disagree				Strongly agree	Strongly disagree				Strongly agree
[Wrinkles]	1	2	3	4	5	1	2	3	4	5
[Elevated cholesterol]	1	2	3	4	5	1	2	3	4	5
[Breast cancer]	1	2	3	4	5	1	2	3	4	5
[Fibromyalgia, chronic pain syndrome]	1	2	3	4	5	1	2	3	4	5
[Elevated blood pressure]	1	2	3	4	5	1	2	3	4	5
[Dental caries]	1	2	3	4	5	1	2	3	4	5
[Lung cancer]	1	2	3	4	5	1	2	3	4	5
[Female menopause]	1	2	3	4	5	1	2	3	4	5
[Malnutrition]	1	2	3	4	5	1	2	3	4	5
[Irritable bowel syndrome]	1	2	3	4	5	1	2	3	4	5
[Homosexuality]	1	2	3	4	5	1	2	3	4	5
[Eye refractive error, need for eyeglasses]	1	2	3	4	5	1	2	3	4	5
[Lactose intolerance]	1	2	3	4	5	1	2	3	4	5
[Down syndrome]	1	2	3	4	5	1	2	3	4	5
[Personality disorder]	1	2	3	4	5	1	2	3	4	5
[Overactive urinary bladder]	1	2	3	4	5	1	2	3	4	5
[Depression]	1	2	3	4	5	1	2	3	4	5
[Juvenile diabetes]	1	2	3	4	5	1	2	3	4	5
[Malaria]	1	2	3	4	5	1	2	3	4	5
[Social anxiety disorder]	1	2	3	4	5	1	2	3	4	5
[Premature ejaculation]	1	2	3	4	5	1	2	3	4	5
[Hip fracture]	1	2	3	4	5	1	2	3	4	5
	Strongly disagree				Strongly agree	Strongly disagree				Strongly

FIND Survey



## States of being perceived as a disease by ≥80% of respondents of all groups

Breast cancer	Lung cancer	Schizophrenia	Adult-onset diabetes
Prostate cancer	Juvenile diabetes	HIV/AIDS	Osteoporosis
Pneumonia	Myocardial infarction	Malaria	Autism

## States of being not perceived as a disease by ≥80% of respondents of all groups

Wrinkles	Smoking	Ageing	Grief
Homosexuality			

## States of being perceived as a disease by at least 20% and not as a disease by at least another 20% of respondents of all groups

Pre-menstrual syndrome, PMS	Infertility	Female menopause	Eye refractive error, need for eyeglasses
Erectile dysfunction	Drug addiction	Malnutrition	Lactose intolerance
Gambling addiction	Age-related muscle loss, sarcopenia		

## Meaning of the study: Implications of alternative viewpoints regarding accepting or rejecting states of being as diseases

- Disparities in views on the fundamental nature of numerous states of being
  - Large differences in views whether states of being should be considered diseases and should be managed through public revenue
- Many states of being can be seen, and consequently treated, differently
  - Biological health disorder / Specific biological problem
  - Lack of self-control / Moral failing
  - Social (mediated adjustment) problem
  - Normal consequence of living / Lifestyle choice
  - Essentialist vs. nominalist

### Implications of alternative viewpoints<sup>1</sup> Example 1: "Diminished function or altered appearance, often age-related"

Category Examples	Disea se?	Conceptualizati on	Implications for action	Potential negative consequences
Diminished function or altered appearance, often age-related  Age-related muscle loss Baldness Erectile dysfunction Lack of sexual desire	Yes	Biological health disorder	Diagnose and treat, possibly with drugs Public funding	Overdiagnosis and overtreatment Medicalization of society, with increased self-perception of illness and poorer coping with suffering that is part of life
	No	Normal consequence of living	Accept and adjust Responsibility on individual	Neglect of treatments that may reduce suffering and improve function

Tikkinen et al. *BMJ Open* 2012:2:e001632

## Implications of alternative viewpoints<sup>1</sup> Example 2: "Addictions or possible addictions"

Category Examples	Disea se?	Concept ualizatio n	Implications for action	Potential negative consequences
Addictions or possible addictions  Alcoholism	Yes	Biological health disorder	Harm reduction Public funding Medical treatment	Focus on individuals and treatments may cause social and moral aspects to be ignored
Drug addiction Gambling addiction Obesity Smoking	No	Lack of self- control Moral failing	Abstinence, self- discipline Punitive management strategies	Stigma and discrimination, neglect of harm reduction/social causes, increased suffering for the population
		Social problem	Income redistribution, poverty reduction, education, social marketing	Effective medical treatment underused

#### Take home messages

- 1. Large differences in the views regarding whether states of being should be considered diseases and managed through public revenue
- 2. Doctors more inclined to consider states of being as diseases, however, disagreement was as evident among health professionals as in other groups
- Understanding people's attitudes about whether states of being should be considered diseases elucidates fundamental underlying attitudes
  - can inform social discourse regarding contentious public policy issues
- 4. Conceptualization of disease is key to issue of overdiagnosis

#### How do we prevent overdiagnosis?

- Overdiagnosis means transforming people to patients unnecessarily (i.e. without clear benefit, and with potential for damage) by identifying problems that were never going to cause harm, or by medicalising ordinary life experiences
- two major causes: overdetection and overdefinition of disease

 Quaternary prevention is: "Action taken to protect individuals (persons/patients) from medical interventions that are likely to cause more harm than good"

### Greetings from PODC 2018

• It is not the matter of Too much medicine, it is the matter of Too much power

# Position Paper on Overdiagnosis and Action to Be Taken (WONCA 2018)

- On behalf of your patients, demand balanced evidence informed and non emotional information material (e.g. invitation brochures) from providers and authorities in relation to cancer screening, health checks, etc.
- Take initiatives to discuss potentials for overdiagnosis in settings where you have influence; in relation to colleagues, GP/FP representative organisations, lay people and health authorities.

## Position Paper on Overdiagnosis and Action to Be Taken

- Demand that authorities and funders put overdiagnosis on the public agenda and support research and dissemination of information on overdiagnosis.
- Initiate and take part in research and professional development related to the problem of overdiagnosis. Share your findings and experience in relevant fora, e.g. the WONCA networks, WONCA Special Interest Groups (SIGs), and congresses.
- Strive to adhere to guidelines and recommendations that aim at reducing unnecessary healthcare, when such recommendations exist.

## Position Paper on Overdiagnosis and Action to Be Taken

- Generally support a professional attitude of moderation among colleagues and students in keeping with the European Definition of General Practice /Family Medicine 2011. Strategies and skills such as 'watchful waiting' and appropriate use of technology must go hand in hand with good communication skills and a practice organization where patients have good access to follow up and return visits.
- Enlist the support of GP/FP organisations to engage critically with stakeholders who are likely to be motivated by competing interests.

#### Council for Choices in Health Care in Finland

- The task of is to issue recommendations on services that should be included in the range of public health services.
- 10.12.2015. Treatment of age-related macular degeneration with intravitreal bevacizumab is included in the publicly funded health service range of Finland
- 30.8.2016 Implant-retained total prosthesis for the treatment of edentulous mandible (included)
- 30.8.2016 Rehabilitation after hip fracture surgery (included)
- 8.2.2017 Knee degeneration treatment by keyhole surgery (excluded)
- 2018 two recommendations...

### **Avoid Wisely Finland**

A model developed by the department of Current Care Guideline of The Finnish Medical Society Duodecim (2016 onwards):

- "Avoid ACE-inhibitors and ATR-blockers during pregnancy"
- = The only avoidable found from Diabetes Current Care guideline (47 pages in pdf format)



Helsingin Sanomat 16.8.2018: Marketing of medicine leads to unnecessary use of them- we are buying sickness in the long term, says a researcher

Elämä

### Lääkemarkkinointi syöttää meille turhia lääkkeitä, sanoo tutkija – "Pitkällä aikavälillä ostamme sairautta"

Lääketiede on kehittynyt niin pitkälle, että kuvantamalla ja tutkimalla löydetään sairauksia, joiden kanssa voisi ihan hyvin elää terveenä, sanovat dosentti Kari Tikkinen ja kanadalainen lääketutkija Alan Cassels.



# Group of Iron deficients in Facebook with 11 000 members



Näytä kaikki



#### Raudanpuute



11 t. jäsentä · Yli 10 julkaisua päivässä

Muistathan vastata miksi haluat ryhmään kun lähetät liittymispyynnön. Muuten emme voi hyväksyä pyyntöäsi. Liitty...

21 jäsentä kertoi käyneensä koulua Kuopion Yliopisto

"A woman deserves a trustworthy partner. You should visit a gynecologist regularly. You will find good one from Terveystalo (private health centre)"



Status of overdiagnosis in Finland; where it still burns and what can be done?

#### Reform of social welfare and health care

Central elements are:

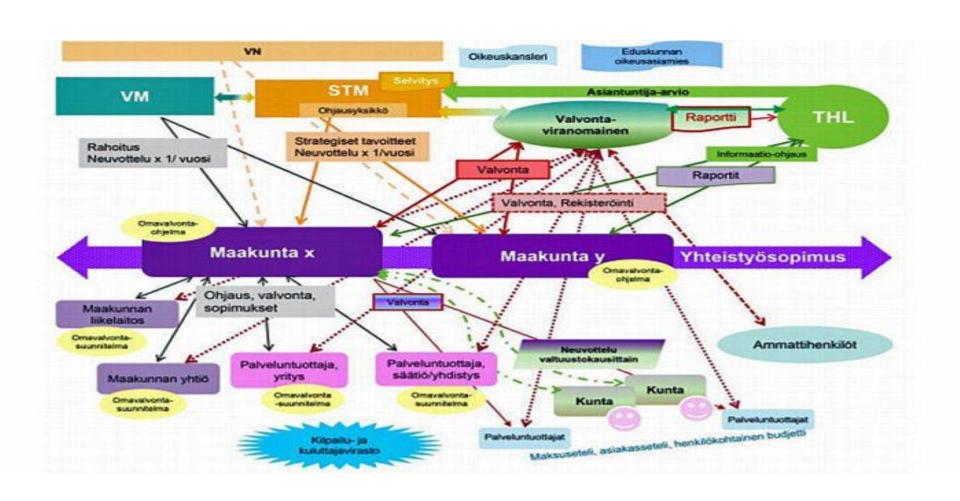
- Privatization
- Free choice

#### What might happen:

Sick people are being undertreated and healthy citizens are being overtreated.



Reform of social welfare and health care: Steering and control in new organization 2019 (reference: government 2017)



# Overdiagnosis-sessions in national conferences

- Overdiagnosis-session Oulu February 2018
- organised by The Finnish Association for General Practice and Oulu University's General Practice dpt:
- 13.20–13.50 Are we making healthy persons sick/ill/diseased?
- Dosentti, urologian erikoistuva lääkäri Kari Tikkinen, HUS ja HY
- 13.50–14.20 How does lab tests are make persons sick/ill/diseased?
- LT, yleislääketieteen erikoislääkäri Seija Eskelinen, Duodecim
- Coffee break
- 14.50–15.20 Real-effectiviness medicine and overdiagnosis
- Dosentti, ylilääkäri Antti Malmivaara, THL
- 15.20–15.50 General practitioner in the frontline at the bifurcation of overdiagnosis and underdiagnosis
- Yleislääketieteen erikoislääkäri Yrjö Perkkiö
- Conversation

# Family Medicine textbook will be published 2020 (earlier 2005)

- Editor –in- chief prof emer Marjukka Mäkelä
- 10 000 marks on Overdiagnosis