When N = way too few

What can qualitative health research actually contribute?

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Today’s talk

Part I: ”I’m tired, tired, tired”

- What is qualitative health research (as distinct from biomedical research)?

Part II: Translational QHR

- Qualitative health research has already contributed to health care in fundamental ways

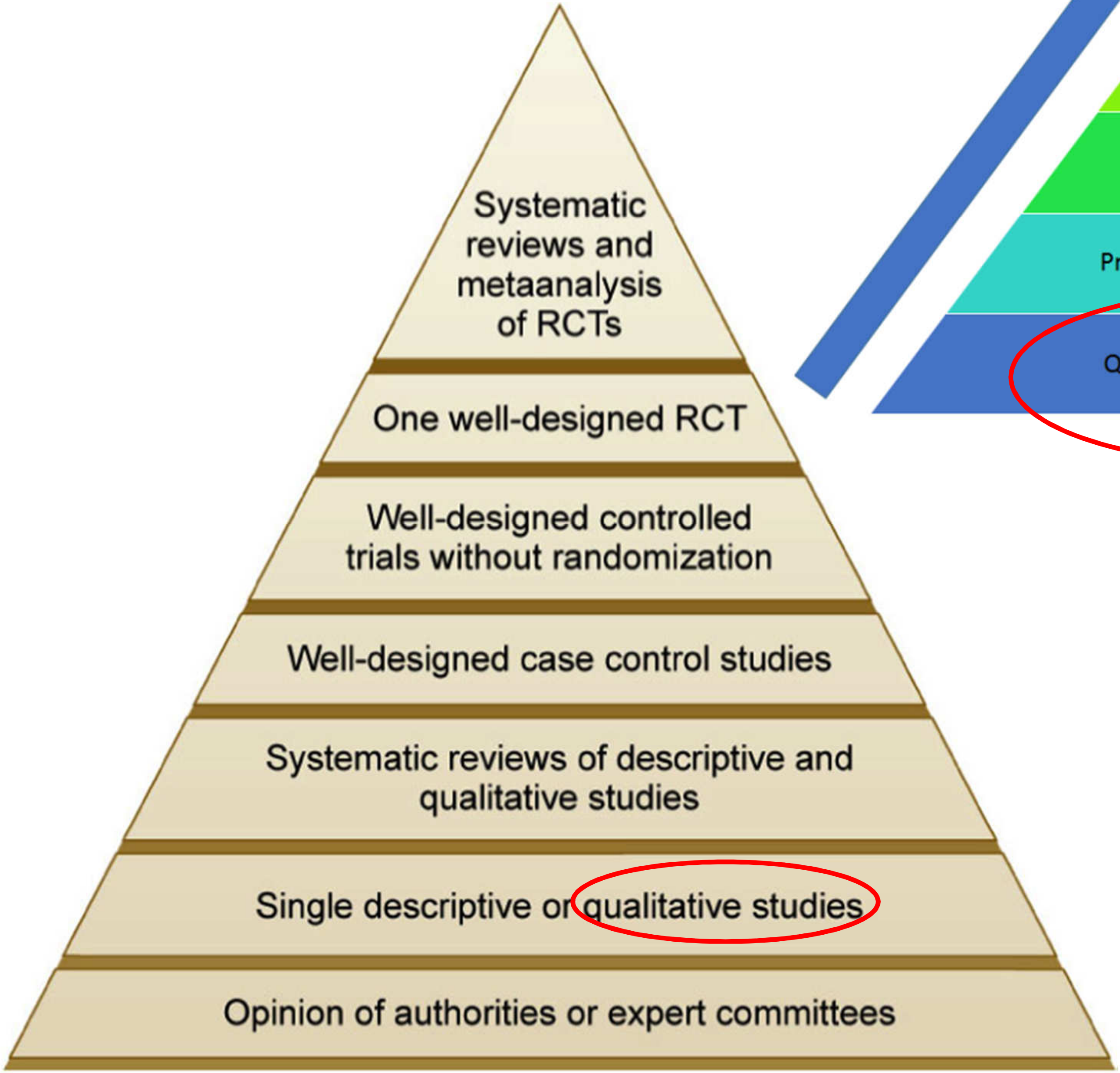
Conclusion: Collaboration is the way forward

Part I

"When I use the word *illness*… I shall mean something fundamentally different from what I mean when I write *disease*. By invoking the term illness, I mean to conjure up the **innately human experience** of symptoms and suffering. Illness refers to how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability…

Disease is the problem from the practitioner's perspective. In the **narrow biological terms of the biomedical model**, this means that disease is reconfigured only as an alteration in biological structure or functioning."

(Kleinman 1988: 3-4)



Systematic reviews and metaanalysis of RCTs

One well-designed RCT

Well-designed controlled trials without randomization

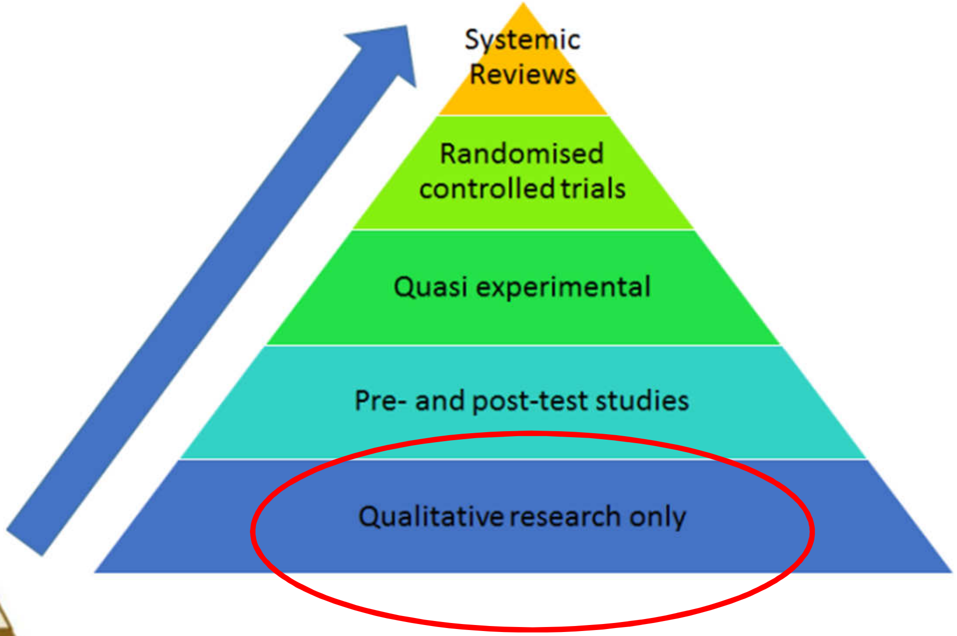
Well-designed case control studies

Systematic reviews of descriptive and qualitative studies

Single descriptive or qualitative studies

Opinion of authorities or expert committees

Modified from Guyatt G, Rennie D: *User's guide to the medical literature*, Chicago, 2002, American Medical Association; Harris RP et al: Current methods of the US Prevention Services Task Force: a review of the process, *Am J Prev Med* 20:21, 2001; Melnyk BM, Fineout-Overholt E: *Evidence-based practice in nursing and healthcare: a guide to best practice*, ed 2, Philadelphia, 2011, Lippincott Williams & Wilkins.



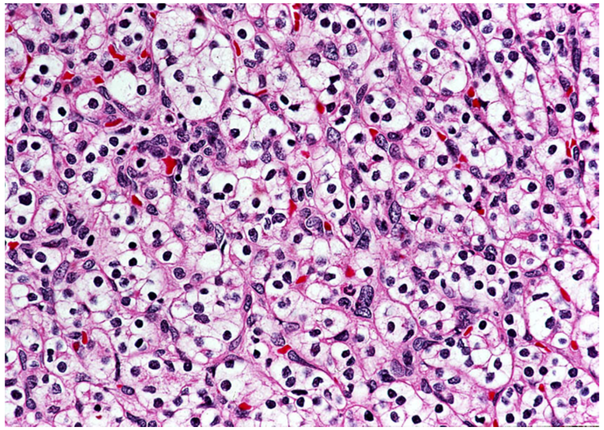
Systemic Reviews

Randomised controlled trials

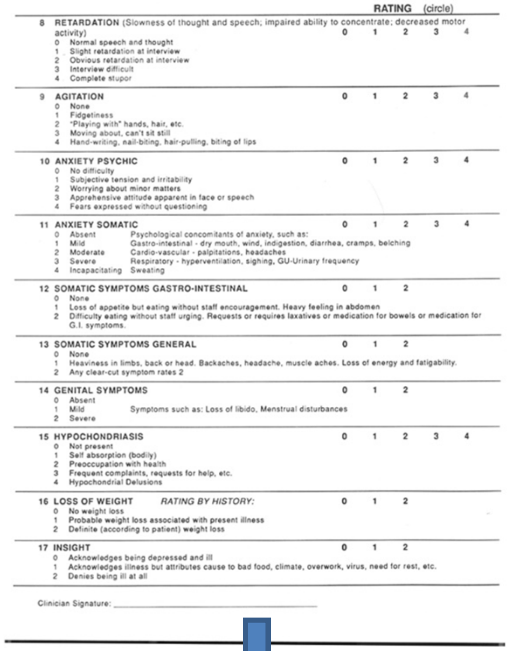
Quasi experimental

Pre- and post-test studies

Qualitative research only



Organs, tissue, cells, DNA



RATING (circle)

8 RETARDATION (Slowness of thought and speech; impaired ability to concentrate; decreased motor activity) 0 1 2 3 4
0 Normal speech and thought
1 Slight retardation at interview
2 Obvious retardation at interview
3 Interview difficult
4 Complete stupor

9 AGITATION 0 1 2 3 4
0 None
1 Fidgetiness
2 "Playing with" hands, hair, etc.
3 Moving about, can't sit still
4 Hand-writing, nail-biting, hair-pulling, biting of lips

10 ANXIETY PSYCHIC 0 1 2 3 4
0 No difficulty
1 Subjective tension and irritability
2 Worrying about minor matters
3 Apprehensive attitude apparent in face or speech
4 Fears expressed without questioning

11 ANXIETY SOMATIC 0 1 2 3 4
0 Absent Psychological concomitants of anxiety, such as:
1 Mild Gastro-intestinal - dry mouth, wind, indigestion, diarrhea, cramps, belching
2 Moderate Cardio-vascular - palpitations, headaches
3 Severe Respiratory - hyperventilation, sighing, GU-Urinary frequency
4 Incapacitating Sweating

12 SOMATIC SYMPTOMS GASTRO-INTESTINAL 0 1 2
0 None
1 Loss of appetite but eating without staff encouragement. Heavy feeling in abdomen
2 Difficulty eating without staff urging. Requests or requires laxatives or medication for bowels or medication for G.I. symptoms.

13 SOMATIC SYMPTOMS GENERAL 0 1 2
0 None
1 Heaviness in limbs, back or head. Backaches, headache, muscle aches. Loss of energy and fatigability.
2 Any clear-cut symptom rates 2

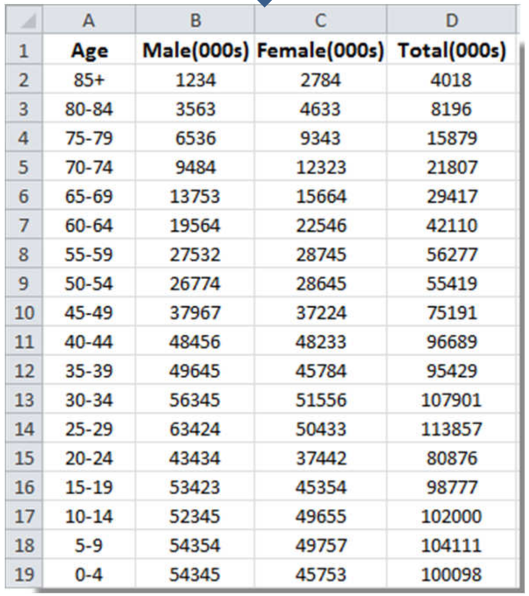
14 GENITAL SYMPTOMS 0 1 2
0 Absent
1 Mild Symptoms such as: Loss of libido, Menstrual disturbances
2 Severe

15 HYPOCHONDRIASIS 0 1 2 3 4
0 Not present
1 Self absorption (bodily)
2 Preoccupation with health
3 Frequent complaints, requests for help, etc.
4 Hypochondrial Delusions

16 LOSS OF WEIGHT *RATING BY HISTORY:* 0 1 2
0 No weight loss
1 Probable weight loss associated with present illness
2 Definite (according to patient) weight loss

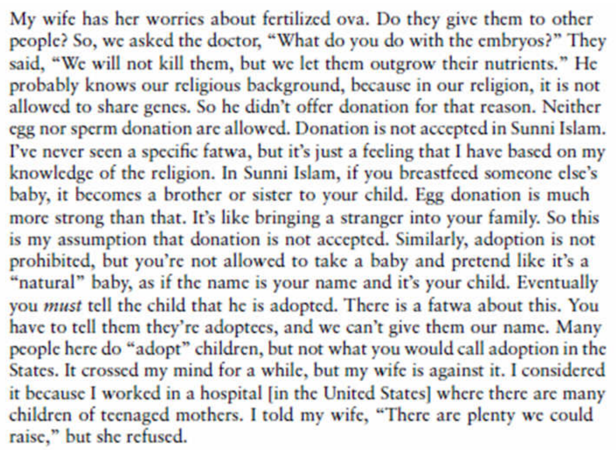
17 INSIGHT 0 1 2
0 Acknowledges being depressed and ill
1 Acknowledges illness but attributes cause to bad food, climate, overwork, virus, need for rest, etc.
2 Denies being ill at all

Clinician Signature: ______________________



	A	B	C	D
1	**Age**	**Male(000s)**	**Female(000s)**	**Total(000s)**
2	85+	1234	2784	4018
3	80-84	3563	4633	8196
4	75-79	6536	9343	15879
5	70-74	9484	12323	21807
6	65-69	13753	15664	29417
7	60-64	19564	22546	42110
8	55-59	27532	28745	56277
9	50-54	26774	28645	55419
10	45-49	37967	37224	75191
11	40-44	48456	48233	96689
12	35-39	49645	45784	95429
13	30-34	56345	51556	107901
14	25-29	63424	50433	113857
15	20-24	43434	37442	80876
16	15-19	53423	45354	98777
17	10-14	52345	49655	102000
18	5-9	54354	49757	104111
19	0-4	54345	45753	100098

Cohorts, populations



My wife has her worries about fertilized ova. Do they give them to other people? So, we asked the doctor, "What do you do with the embryos?" They said, "We will not kill them, but we let them outgrow their nutrients." He probably knows our religious background, because in our religion, it is not allowed to share genes. So he didn't offer donation for that reason. Neither egg nor sperm donation are allowed. Donation is not accepted in Sunni Islam. I've never seen a specific fatwa, but it's just a feeling that I have based on my knowledge of the religion. In Sunni Islam, if you breastfeed someone else's baby, it becomes a brother or sister to your child. Egg donation is much more strong than that. It's like bringing a stranger into your family. So this is my assumption that donation is not accepted. Similarly, adoption is not prohibited, but you're not allowed to take a baby and pretend like it's a "natural" baby, as if the name is your name and it's your child. Eventually you *must* tell the child that he is adopted. There is a fatwa about this. You have to tell them they're adoptees, and we can't give them our name. Many people here do "adopt" children, but not what you would call adoption in the States. It crossed my mind for a while, but my wife is against it. I considered it because I worked in a hospital [in the United States] where there are many children of teenaged mothers. I told my wife, "There are plenty we could raise," but she refused.

Identities,socialities, practices

Populations *have* disease(s)

- Incidence, prevalence
- Disease burdens
- Mortality & morbidity rates
- Lifestyle factors
- Environmental exposures
- Health policy and prioritisation
- Cost-effectiveness

Populations, cohorts

Patients *have* disease(s)

- Requires clinical care
- Diagnostics
- Therapeutics
- Pharmaceuticals
- Hospitalisation, testing, monitoring
- Managing side effects
- Surveillance, rehabilitation

Tissue, cells, DNA

Families *live with* disease(s)

- Making sense of
- Disruption of daily lives and routines
- Developing therapeutic itineraries
- Managing and coordinating family daily life
- Living with disease

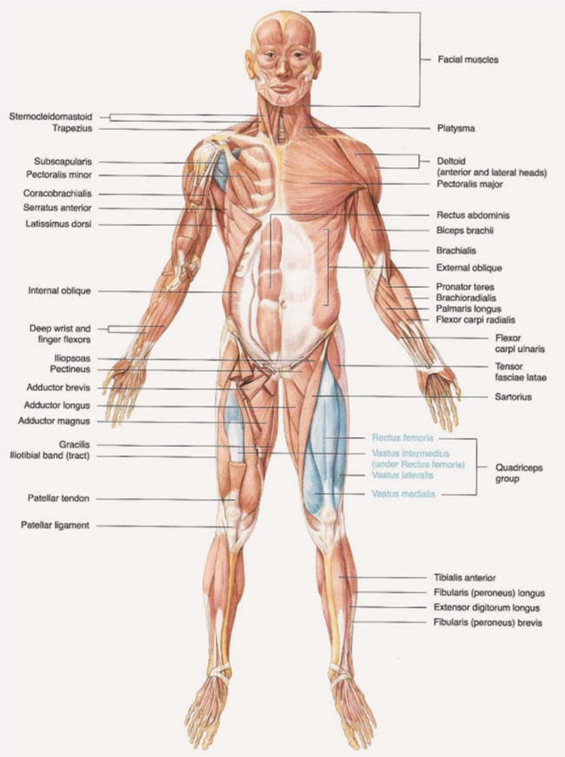
Lifeworlds, experiences, practices, socialities

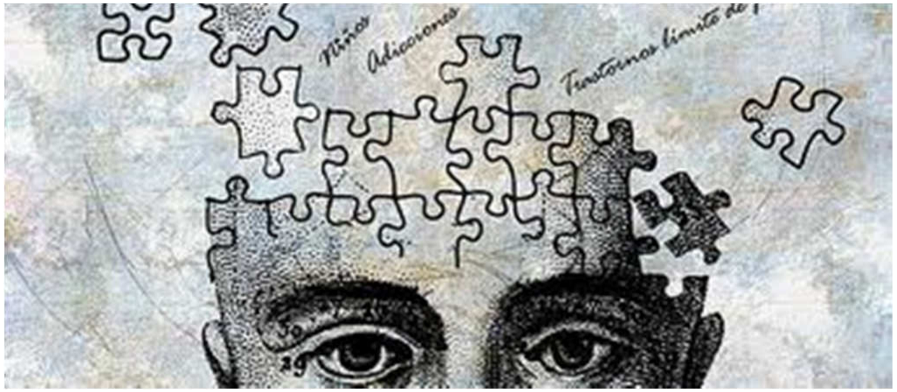
Individuals *cope with* disease(s)

- Shock, anguish, anger, grief, confusion
- Anxiety, stress, depression
- Coping techniques
- Building resilience
- Psychological counselling
- Coping with disease

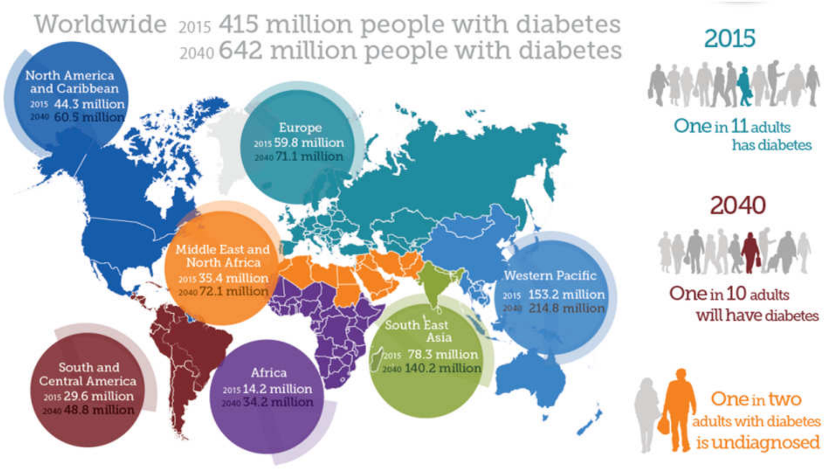
Psyches, personalities, self

Research objects

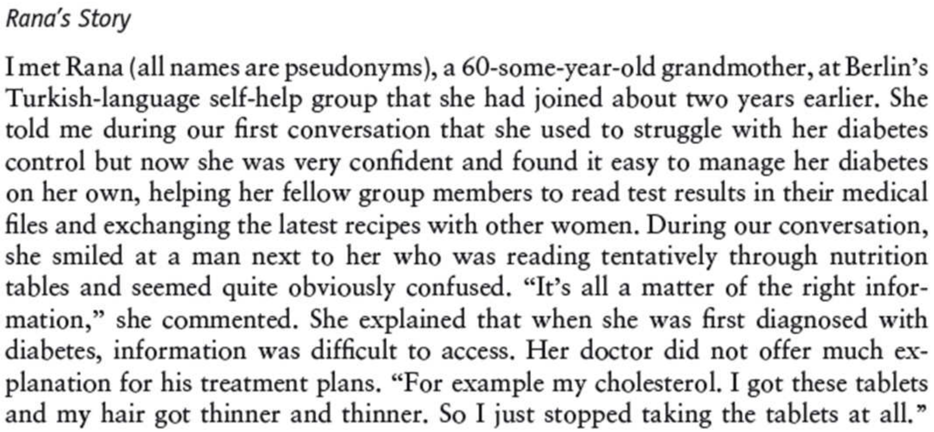




Diabetes



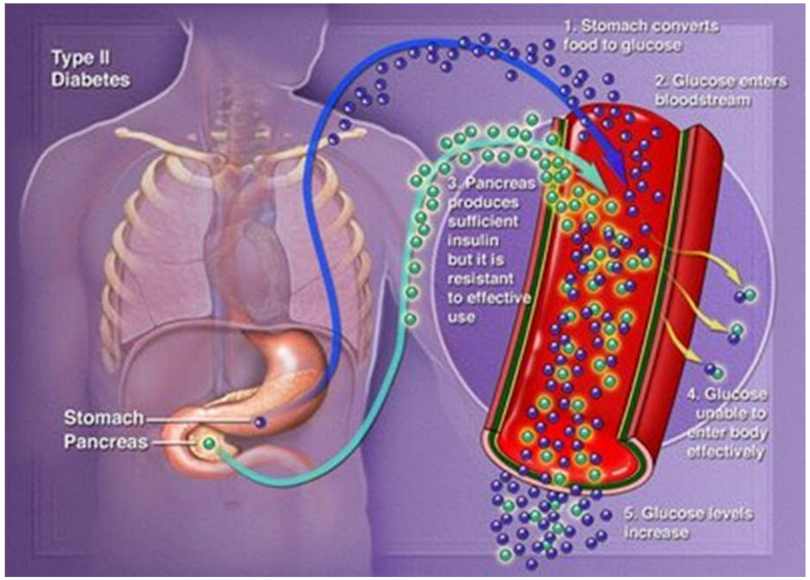
(IDF 2015)



Rana's Story

I met Rana (all names are pseudonyms), a 60-some-year-old grandmother, at Berlin's Turkish-language self-help group that she had joined about two years earlier. She told me during our first conversation that she used to struggle with her diabetes control but now she was very confident and found it easy to manage her diabetes on her own, helping her fellow group members to read test results in their medical files and exchanging the latest recipes with other women. During our conversation, she smiled at a man next to her who was reading tentatively through nutrition tables and seemed quite obviously confused. "It's all a matter of the right information," she commented. She explained that when she was first diagnosed with diabetes, information was difficult to access. Her doctor did not offer much explanation for his treatment plans. "For example my cholesterol. I got these tablets and my hair got thinner and thinner. So I just stopped taking the tablets at all."

(Guell 2012)



(MedFriendly 2016)

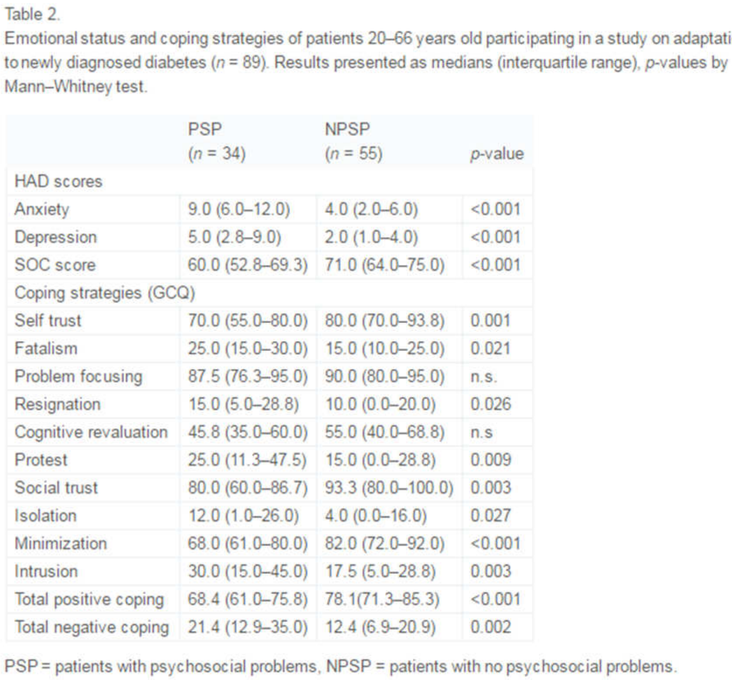


Table 2.
Emotional status and coping strategies of patients 20–66 years old participating in a study on adaptation to newly diagnosed diabetes (n = 89). Results presented as medians (interquartile range), p-values by Mann–Whitney test.

	PSP (n = 34)	NPSP (n = 55)	p-value
HAD scores			
Anxiety	9.0 (6.0–12.0)	4.0 (2.0–6.0)	<0.001
Depression	5.0 (2.8–9.0)	2.0 (1.0–4.0)	<0.001
SOC score	60.0 (52.8–69.3)	71.0 (64.0–75.0)	<0.001
Coping strategies (GCQ)			
Self trust	70.0 (55.0–80.0)	80.0 (70.0–93.8)	0.001
Fatalism	25.0 (15.0–30.0)	15.0 (10.0–25.0)	0.021
Problem focusing	87.5 (76.3–95.0)	90.0 (80.0–95.0)	n.s.
Resignation	15.0 (5.0–28.8)	10.0 (0.0–20.0)	0.026
Cognitive revaluation	45.8 (35.0–60.0)	55.0 (40.0–68.8)	n.s
Protest	25.0 (11.3–47.5)	15.0 (0.0–28.8)	0.009
Social trust	80.0 (60.0–86.7)	93.3 (80.0–100.0)	0.003
Isolation	12.0 (1.0–26.0)	4.0 (0.0–16.0)	0.027
Minimization	68.0 (61.0–80.0)	82.0 (72.0–92.0)	<0.001
Intrusion	30.0 (15.0–45.0)	17.5 (5.0–28.8)	0.003
Total positive coping	68.4 (61.0–75.8)	78.1(71.3–85.3)	<0.001
Total negative coping	21.4 (12.9–35.0)	12.4 (6.9–20.9)	0.002

PSP = patients with psychosocial problems, NPSP = patients with no psychosocial problems.

(Rane et al. 2011)

So what is qualitative health research (in social science)?

- systematic collection of empirical data through (participant) observation, interviews and/or collection of written/audio-visual materials to generate analytical insight into more or less shared ways of <u>thinking</u>, <u>doing</u> or <u>being</u>:

  - how individuals and groups perceive, orient themselves and make sense of their surroundings through **patterned forms of thought**

  - how individuals and groups organise themselves and interact with others through **regularised practices** over time

  - how individuals **experience** their everyday lives in embodied, yet shaped ways

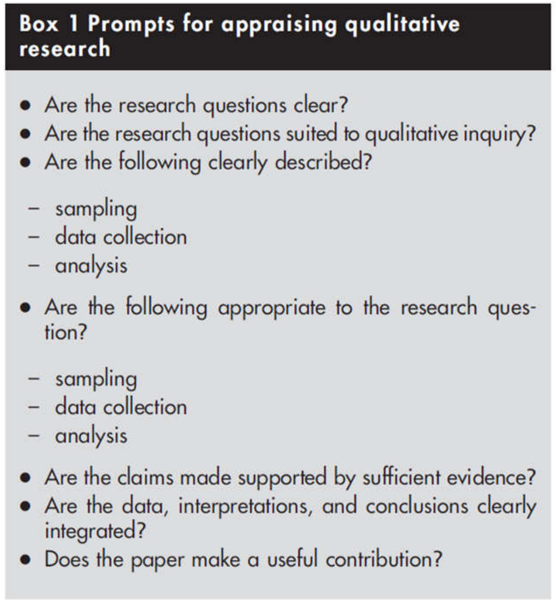
Qualitative data sets

- Field notes
- Interview transcripts (audio recordings)
- Grey literature – brochures, leaflets, guides
- Social media postings
- Media stories
- Pictures, video recordings

Semantic/semiotic patterns in textual data sets rather than numerical patterns in quantitative data sets

N=way too few?

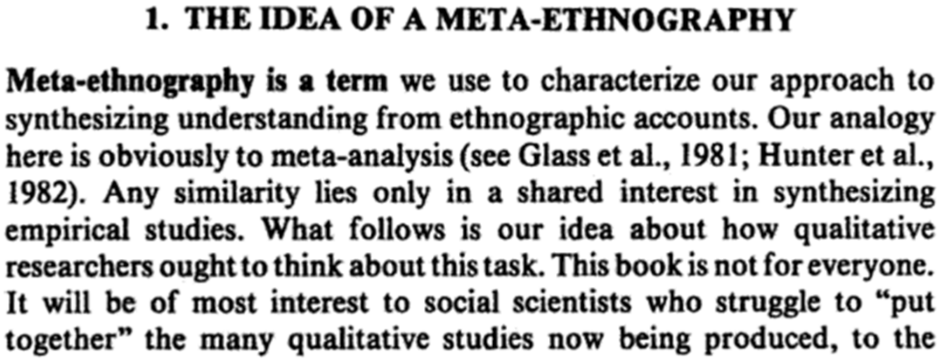
- Power from depth, not breadth
- Depth requires time (as does breadth)
- Researcher–informant relations
- Good quality data requires trust, intimacy, sustained relations
- This does not mean that N-breadth, N-representativity is irrelevant
- But there are breadth-depth trade-offs



Box 1 Prompts for appraising qualitative research

- Are the research questions clear?
- Are the research questions suited to qualitative inquiry?
- Are the following clearly described?
  - sampling
  - data collection
  - analysis
- Are the following appropriate to the research question?
  - sampling
  - data collection
  - analysis
- Are the claims made supported by sufficient evidence?
- Are the data, interpretations, and conclusions clearly integrated?
- Does the paper make a useful contribution?

(Dixon-Woods et al. 2004)



1. THE IDEA OF A META-ETHNOGRAPHY

Meta-ethnography is a term we use to characterize our approach to synthesizing understanding from ethnographic accounts. Our analogy here is obviously to meta-analysis (see Glass et al., 1981; Hunter et al., 1982). Any similarity lies only in a shared interest in synthesizing empirical studies. What follows is our idea about how qualitative researchers ought to think about this task. This book is not for everyone. It will be of most interest to social scientists who struggle to "put together" the many qualitative studies now being produced, to the

(Nolbit & Hare 1988)

Table 1
Consistency of assessment

Assessment questions	Agree	Partially agree	Disagree	other
1. *Is this qualitative research?*	7			
2. Relevant to synthesis	7			
3. Aims	6		1	
4. Qualitative methods appropriate	X	X	X	X
5a. Theoretical perspective identified	5	1	1	
5b. Which theoretical perspective	5	1		1
6a. Sample where	5	2		
6b. Setting why	5		1	1
6c.Who selected	5	2		
6d.Why sample selected	4		3	
6e. How sample selected	2	2	2	1
6f. Sample size	5	1	1	
6g. How many refused	5	1	1	
6h. Why refused	6			1
6i. Adequate info. on characteristics	5	2		
Sampling strategy appropriate?	3	2		2
7a. Setting data collection	6	1		
7b. Setting chosen	4	2	1	
7c. Purpose explained	5		1	1
7d. How data collected	4	3		
7e. Why data collected	3	2	2	
7f. How data recorded	7			
7g. Whether methods modified	6		1	
7h. Who collected data	6		1	
Data collection address research issue?	6		1	
8a. How the analysis was done	5	1	1	
8b. Categories derived	5	1		1
8c. Adequate description	5	1	1	
8d. Feedback	6	1		
8e. Different sources	4	2	1	
8f. Reliability	6			
Data analysis rigorous?	5	2		
9a. Examine role	6		1	
9b. Relationship between researchers	7			
10a. Possible to summarise findings	7			
10b. Findings explicit	6	1		
Key concepts				
11a. Sufficient data presented	2	1	3	1
11b. Quotes identified	6	0		1
11c. Data selection explained	4	0	2	1
11d. Links between data and interpretations	1	1	4	1
11e. Negative cases	4	0	3	
11f. Discussion for and against	4	0	3	
All data taken into account?	5	0	1	1
12a. Congruence	X	X	X	X
12b. Transferable	4	2	1	
13a. How useful to synthesis	X	X	X	X
13b. How important findings to practice	6	1		
14a. Overall assessment	2	3		2
14b. Include in synthesis?	7			

(Campbell et al. 2003)

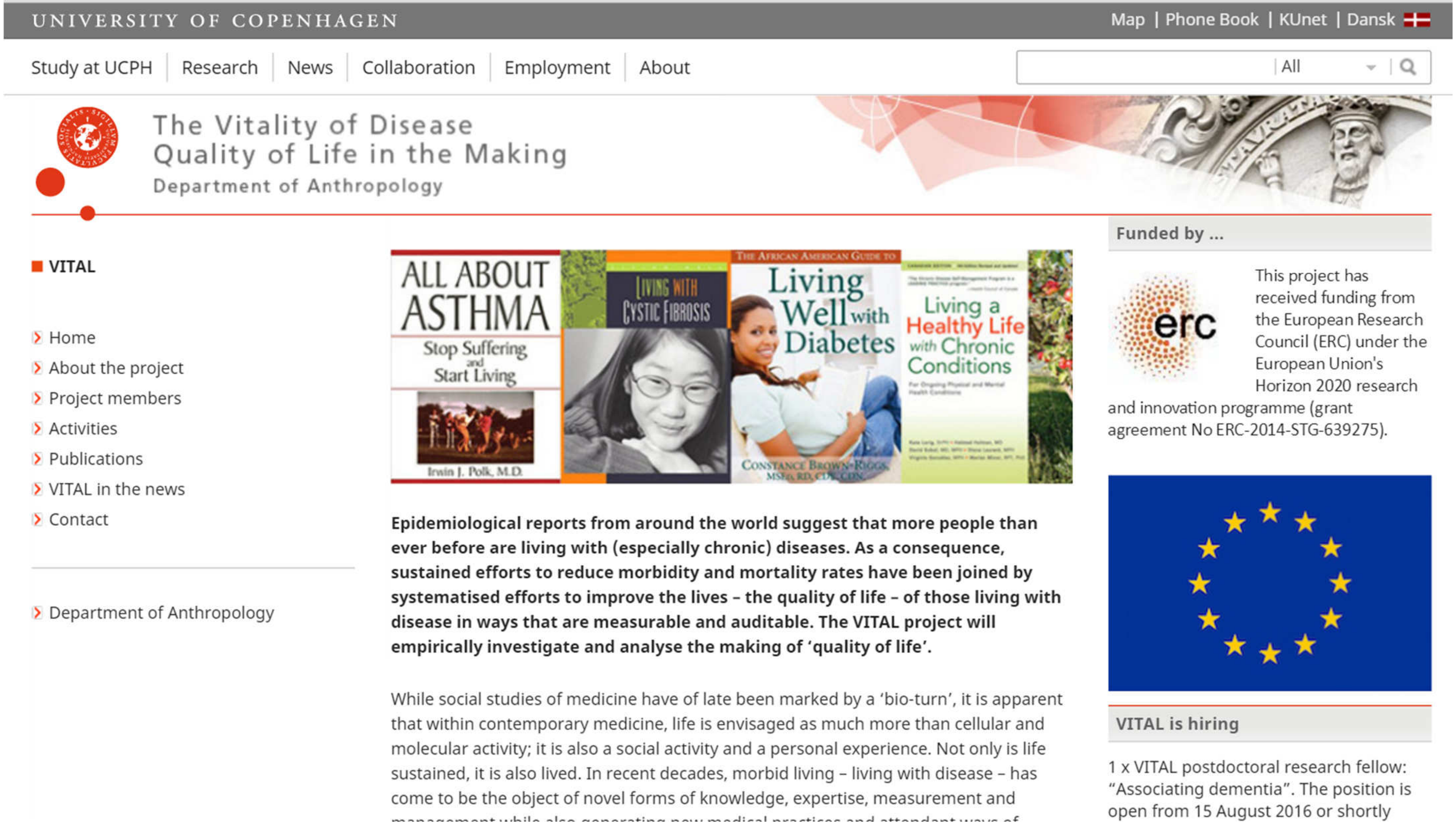
I’m tired, tired, tired…

- Enough with slamming the evidence bases, methodologies, knowledges of other forms of research
- Enough with the single evidence hierarchy – each form of research has its hierarchies of rigour
- Rigour is not up for debate – every discipline, approach is responsible for upholding the highest standards
- No discipline or approach is under any more or less obligation to defend/justify its standards of rigour

Part II

The impact of
qualitative health research

(with a particular focus on medical anthropology)



The Vitality of Disease
Quality of Life in the Making
Department of Anthropology

Epidemiological reports from around the world suggest that more people than ever before are living with (especially chronic) diseases. As a consequence, sustained efforts to reduce morbidity and mortality rates have been joined by systematised efforts to improve the lives – the quality of life – of those living with disease in ways that are measurable and auditable. The VITAL project will empirically investigate and analyse the making of 'quality of life'.

While social studies of medicine have of late been marked by a 'bio-turn', it is apparent that within contemporary medicine, life is envisaged as much more than cellular and molecular activity; it is also a social activity and a personal experience. Not only is life sustained, it is also lived. In recent decades, morbid living – living with disease – has come to be the object of novel forms of knowledge, expertise, measurement and management while also generating new medical practices and attendant ways of

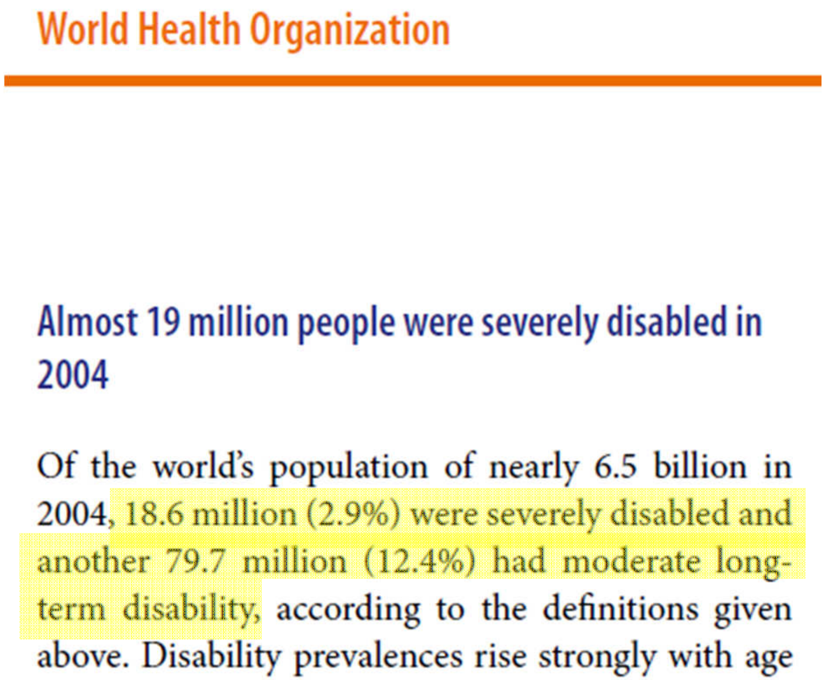
Funded by ...

This project has received funding from the European Research Council (ERC) under the European Union's Horizon 2020 research and innovation programme (grant agreement No ERC-2014-STG-639275).

VITAL is hiring

1 x VITAL postdoctoral research fellow: "Associating dementia". The position is open from 15 August 2016 or shortly

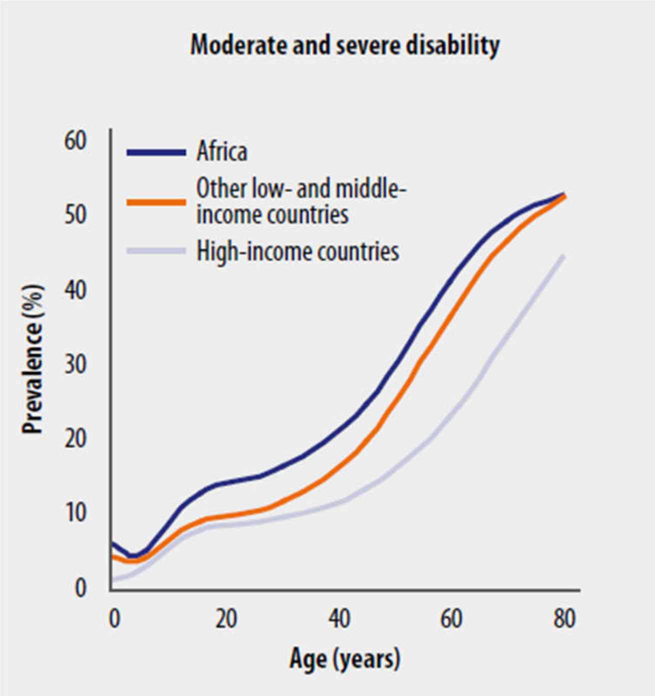
More people than ever before **are living with their diseases**



World Health Organization

Almost 19 million people were severely disabled in 2004

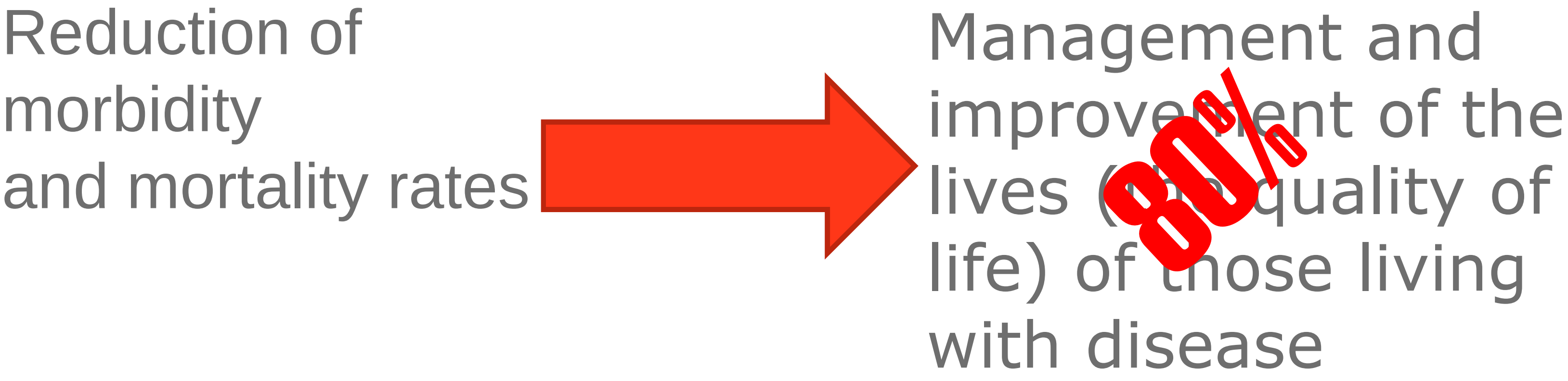
Of the world's population of nearly 6.5 billion in 2004, 18.6 million (2.9%) were severely disabled and another 79.7 million (12.4%) had moderate long-term disability, according to the definitions given above. Disability prevalences rise strongly with age



…health objectives are changing

“many diseases or conditions are not fatal but are responsible for great loss of healthy life… the losses that occur this side of death because of handicap, pain, or other disability.”

(World Bank 1993)



Reduction of morbidity and mortality rates

Management and improvement of the lives (the quality of life) of those living with disease

80%

"In recent years, average life expectancy has increased significantly more in Denmark than in those countries we normally compare ourselves to… But it is not only about length of life. **At least as important is quality of life**. Preventative and health promoting efforts must be directed towards **both lengthening life and improving quality of life**. It is the view of this government that this approach be broadly adopted such that we focus much more than hitherto on both length and quality of life, not least quality of life in the years after work life when major diseases are more prevalent. It is crucial for a good life to avoid disease. And should one get a chronic illness to get the possibility to and support for living a life of good quality."

(Healthy for Life, Government of Denmark 2002)

Sund hele livet

– de nationale mål og strategier
for folkesundheden 2002-10

Regeringen
September 2002

4 examples of the impact of QHR

- The adjustment of epidemiological measurements of the health of populations – DALYs, QALYs, DALEs, HALEs
- development of instruments, rating scales and indices – such as the EQ-5D health outcomes instrument – to measure how it is to live with a certain disease;
- proliferation of ‘expert patient’ courses by health authorities where chronically ill patients are taught to treat and manage their own health conditions;
- emergence and consolidation of systematised ‘Living with’-guides for patients and carers (see Figure 1), often prepared by patient or disease-advocacy associations;

1. Epidemiological calculation

Economy and Society Volume 00 Number 00 Month 2015: 1–31
http://dx.doi.org/10.1080/03085147.2014.983830

The governmentalization of living: calculating global health

Ayo Wahlberg and Nikolas Rose*

After mortality

“there is a difficulty inherent in the use of mortality statistics as measures of health status. They tell little about the *living*, while the health of the living has become a very important aspect of health status.”

(‘Conceptual problems in developing an index of health’, Daniel Sullivan 1966)

From morbid death to morbid living

A gradual shift in/multiplying of epidemiological styles of thinking over the course of the 20C – from loss of life (death) to loss of ‘healthy life’ (QoL)

Adjusting vital calculation: diseases are not only something people have and eventually die from (birth rates, mortality rates, morbidity rates, life expectancy, etc.), they are also something that people *live with* (disability weights, discomfort continuums, healthy life expectancy)

Metrics of incidence, prevalence and mortality have been supplemented by a metrics of severity and impairment

“The problem is no longer merely one of finitude, of the extinction of life by death: the problem space now concerns the loss of the mode of life proper to vitality consequent on the impact of disease on the individual and collective. Accordingly, to assess the health of a population it is not sufficient to count the dead and record what they died from: we must study the ‘costs’ of disease for ‘the living’ – for each and for all – and how they individually and collectively suffer from, and cope with, the diseases with which they live.”

(Wahlberg & Rose 2015)

2. Clinical trials

Top 10 prescription drugs

Drug	**Condition**	**Sales 2005**
LIPITOR (Pfizer)	High cholesterol	$12.9 billion
PLAVIX (Bristol-Meyers)	Heart disease	$5.9 billion
NEXIUM (AstraZeneca)	Heartburn	$5.7 billion
SERETIDE (GSK)	Asthma	$5.6 billion
ZOCOR (Merck)	High cholesterol	$5.3 billion
NORVASC (Pfizer)	High blood pressure	$5.0 billion
ZYPREXA (Eli Lilly)	Schizophrenia	$4.7 billion
RISPERDAL (J&J)	Schizophrenia	$4.0 billion
PREVACID (Abb. & Tak.)	Heartburn	$4.0 billion
EFFEXOR XR (Wyeth)	Depression	$3.8 billion

Forbes 2006

Therapeutic claims

“Olanzapine [**Zyprexa**] demonstrated a superiority over risperidone in reducing mood symptoms, providing high clinical response rates, maintaining response and **improving patient quality of life** and interpersonal relationships.”

“After treatment with **Nexium** 91% of patients with reflux esophagitis in the study shown here were free of heartburn, resulting in a considerable **improvement** in many aspects of their daily lives (assessed using the **Quality of Life** in Reflux and Dyspepsia [QOLRAD] questionnaire)”

“**Advair** significantly **improved** and maintained health-related **quality of life**, with the average improvement in the St. George’s Respiratory Questionnaire (SGRQ) total score for Advair being a reduction of 3.1 units compared with placebo”

“Subjects treated with venlafaxine [**Effexor**] noted a reduction in severity of hot flushes and **improved quality of life** as compared to those receiving placebo”

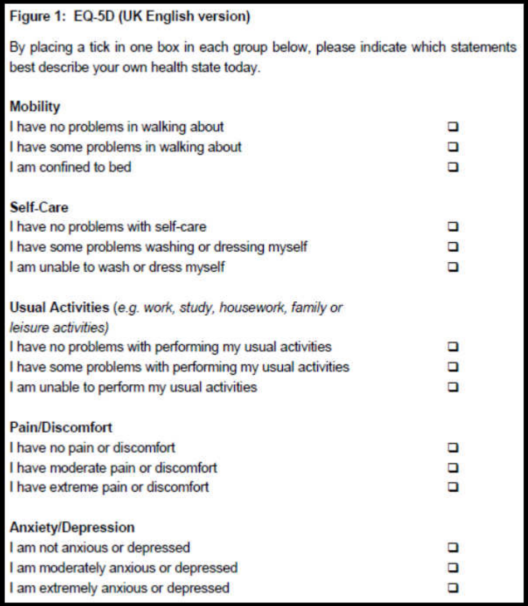


Figure 1: EQ-5D (UK English version)

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility
I have no problems in walking about ☐
I have some problems in walking about ☐
I am confined to bed ☐

Self-Care
I have no problems with self-care ☐
I have some problems washing or dressing myself ☐
I am unable to wash or dress myself ☐

Usual Activities (*e.g. work, study, housework, family or leisure activities*)
I have no problems with performing my usual activities ☐
I have some problems with performing my usual activities ☐
I am unable to perform my usual activities ☐

Pain/Discomfort
I have no pain or discomfort ☐
I have moderate pain or discomfort ☐
I have extreme pain or discomfort ☐

Anxiety/Depression
I am not anxious or depressed ☐
I am moderately anxious or depressed ☐
I am extremely anxious or depressed ☐

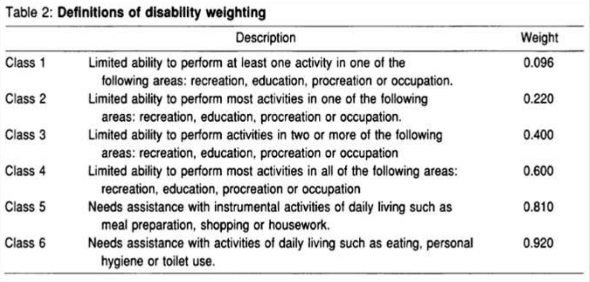


Table 2: **Definitions of disability weighting**

	Description	Weight
Class 1	Limited ability to perform at least one activity in one of the following areas: recreation, education, procreation or occupation.	0.096
Class 2	Limited ability to perform most activities in one of the following areas: recreation, education, procreation or occupation.	0.220
Class 3	Limited ability to perform activities in two or more of the following areas: recreation, education, procreation or occupation	0.400
Class 4	Limited ability to perform most activities in all of the following areas: recreation, education, procreation or occupation	0.600
Class 5	Needs assistance with instrumental activities of daily living such as meal preparation, shopping or housework.	0.810
Class 6	Needs assistance with activities of daily living such as eating, personal hygiene or toilet use.	0.920

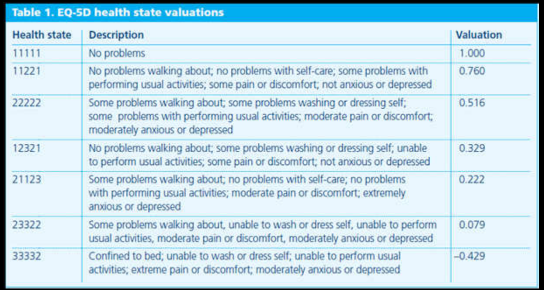


Table 1. EQ-5D health state valuations

Health state	Description	Valuation
11111	No problems	1.000
11221	No problems walking about; no problems with self-care; some problems with performing usual activities; some pain or discomfort; not anxious or depressed	0.760
22222	Some problems walking about; some problems washing or dressing self; some problems with performing usual activities; moderate pain or discomfort; moderately anxious or depressed	0.516
12321	No problems walking about; some problems washing or dressing self; unable to perform usual activities; some pain or discomfort; not anxious or depressed	0.329
21123	Some problems walking about; no problems with self-care; no problems with performing usual activities; moderate pain or discomfort; extremely anxious or depressed	0.222
23322	Some problems walking about, unable to wash or dress self, unable to perform usual activities, moderate pain or discomfort, moderately anxious or depressed	0.079
33332	Confined to bed; unable to wash or dress self; unable to perform usual activities; extreme pain or discomfort; moderately anxious or depressed	–0.429

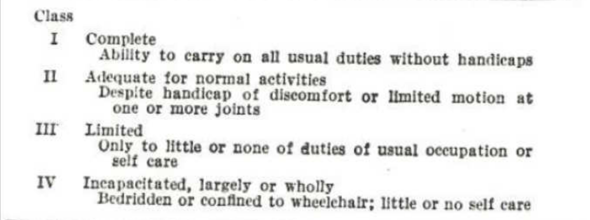
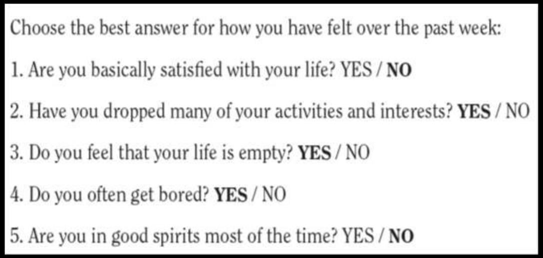


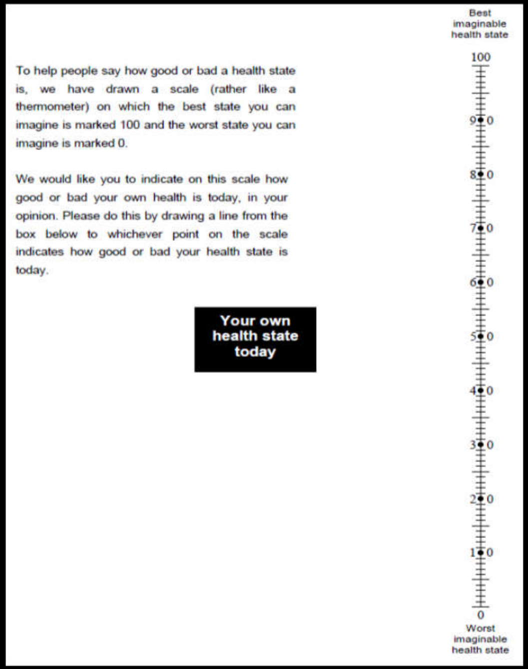
TABLE 2.—*Classification of Functional Capacity*

Class	
I	Complete Ability to carry on all usual duties without handicaps
II	Adequate for normal activities Despite handicap of discomfort or limited motion at one or more joints
III	Limited Only to little or none of duties of usual occupation or self care
IV	Incapacitated, largely or wholly Bedridden or confined to wheelchair; little or no self care



Choose the best answer for how you have felt over the past week:

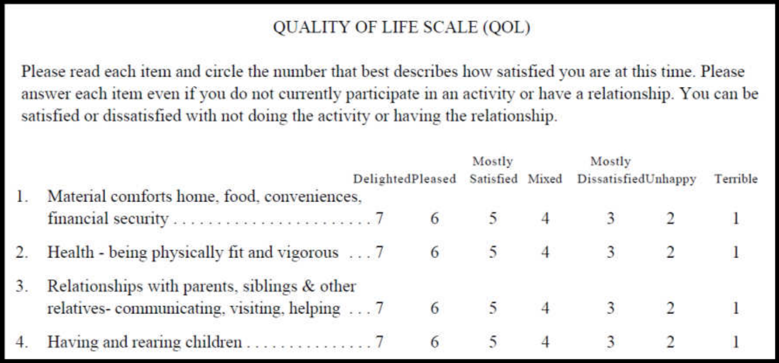
1. Are you basically satisfied with your life? YES / **NO**
2. Have you dropped many of your activities and interests? **YES** / NO
3. Do you feel that your life is empty? **YES** / NO
4. Do you often get bored? **YES** / NO
5. Are you in good spirits most of the time? YES / **NO**



To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

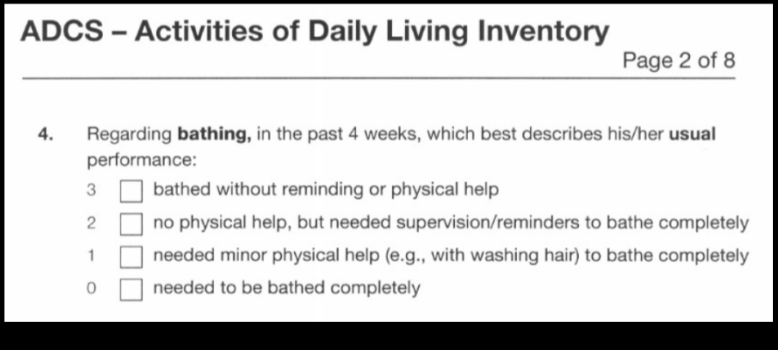
Your own health state today



QUALITY OF LIFE SCALE (QOL)

Please read each item and circle the number that best describes how satisfied you are at this time. Please answer each item even if you do not currently participate in an activity or have a relationship. You can be satisfied or dissatisfied with not doing the activity or having the relationship.

	Delighted	Pleased	Mostly Satisfied	Mixed	Mostly Dissatisfied	Unhappy	Terrible
1. Material comforts home, food, conveniences, financial security	7	6	5	4	3	2	1
2. Health - being physically fit and vigorous . . .	7	6	5	4	3	2	1
3. Relationships with parents, siblings & other relatives- communicating, visiting, helping . . .	7	6	5	4	3	2	1
4. Having and rearing children	7	6	5	4	3	2	1



ADCS – Activities of Daily Living Inventory

Page 2 of 8

4. Regarding **bathing,** in the past 4 weeks, which best describes his/her **usual** performance:

3 ☐ bathed without reminding or physical help
2 ☐ no physical help, but needed supervision/reminders to bathe completely
1 ☐ needed minor physical help (e.g., with washing hair) to bathe completely
0 ☐ needed to be bathed completely

The standardised subject

What is it like for someone to live with a disease, what is morbid living like? => An entire archive of rating scales, indices and instruments which aim to measure the impact of disease on *daily living*.

“the losses that occur this side of death because of handicap, pain, or other disability” (World Bank 1993).

Premise: disease is debilitating, becoming sick will eventually impact on your daily life through a range of restrictions, limitations, constraints, discomforts and apprehensions. By scoring and ranking these, rating scales provide a numerical basis for assessing disease impact along axes of severity.

Four domains of daily living

1) **Functional ability** – many rating scales give priority to ‘performance’ or the ability to carry out daily activities such as self-care (washing, toilet visits), mobility, cleaning, cooking, shopping, etc. Continuums go from ‘bedridden’ or ‘entirely dependent’ to ‘fully mobile’ or ‘independent’.

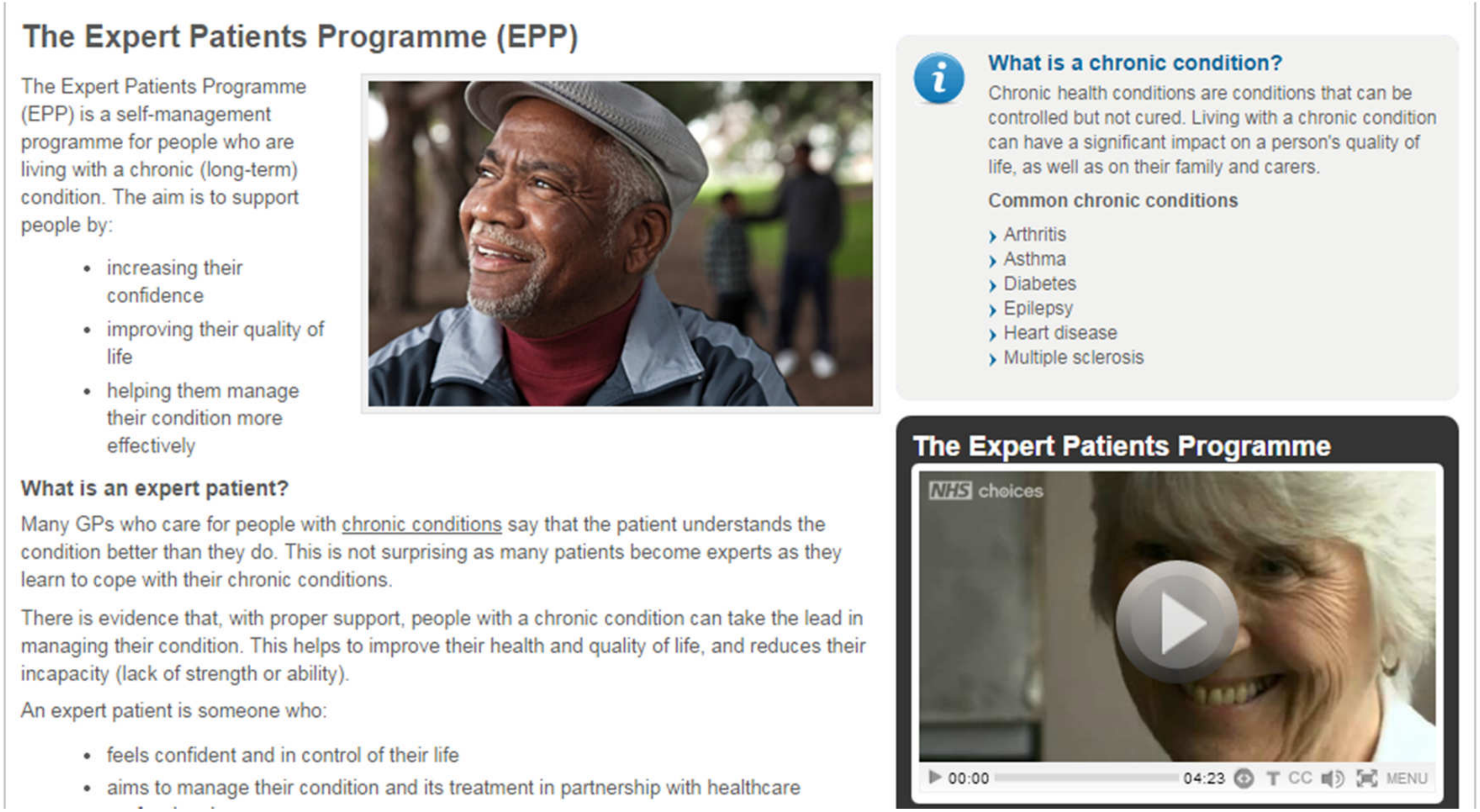
2) **Discomfort** – not only is sickness seen to limit or constrain, it also generates discomfort, a point that many rating scales attempt to capture by asking patients to what extent they feel pain or discomfort. Continuums go from extreme pain/suffering to no pain or discomfort.

3) **Unease** – some rating scales attempt to capture the many apprehensions that sickness can generate in a patient. Continuums range from ‘very anxious or depressed’ to ‘not anxious or depressed’

4) **Relationships** – a less common domain is that of relationships which suggests that a ‘thriving’ person is one who is involved in a number of positive relationships with family, friends and colleagues. Continuums can be organised along degrees of isolation (i.e. number of relationships) as well as on how individuals assess their relationships (e.g. as good or bad).

3. Expert patient schools

Expert patients



The Expert Patients Programme (EPP)

The Expert Patients Programme (EPP) is a self-management programme for people who are living with a chronic (long-term) condition. The aim is to support people by:

- increasing their confidence
- improving their quality of life
- helping them manage their condition more effectively

What is an expert patient?

Many GPs who care for people with chronic conditions say that the patient understands the condition better than they do. This is not surprising as many patients become experts as they learn to cope with their chronic conditions.

There is evidence that, with proper support, people with a chronic condition can take the lead in managing their condition. This helps to improve their health and quality of life, and reduces their incapacity (lack of strength or ability).

An expert patient is someone who:

- feels confident and in control of their life
- aims to manage their condition and its treatment in partnership with healthcare

What is a chronic condition?

Chronic health conditions are conditions that can be controlled but not cured. Living with a chronic condition can have a significant impact on a person's quality of life, as well as on their family and carers.

Common chronic conditions

- › Arthritis
- › Asthma
- › Diabetes
- › Epilepsy
- › Heart disease
- › Multiple sclerosis

The Expert Patients Programme

"When you come home from the hospital after treatment for a heart disease, it can be difficult to imagine how daily life will be. Recovery takes time and you need to know how to prevent your heart disease from getting worse. In this brochure you can read about our offer of courses and training for heart patients after discharge."

(Hvidovre Hospital 2010).

Patientskole

En patientskole er et kursus for patienter om et fælles emne, der berører hver enkelt patient, der deltager. Det kan være kurser for patienter med diabetes eller en hjertesygdom.

Hvordan finder jeg ud af, at der findes en patientskole om min sygdom?

På kurserne kan man fx få mere viden om sygdom og behandlingsmuligheder. Man kan også høre mere de muligheder, man har for at øge sin livskvalitet på trods af sygdommen.

Hvis der findes en patientskole for din sygdom, får du besked af den afdeling, du er tilknyttet.

Patient navigator: A role that goes beyond clinical care

Cancer entails a confusing labyrinth of multidisciplinary care. Using nurses in this role is becoming increasingly vital to achieving ideal patient outcomes.

ROSE LISANO VALENTINO, MSN, FNP, BC

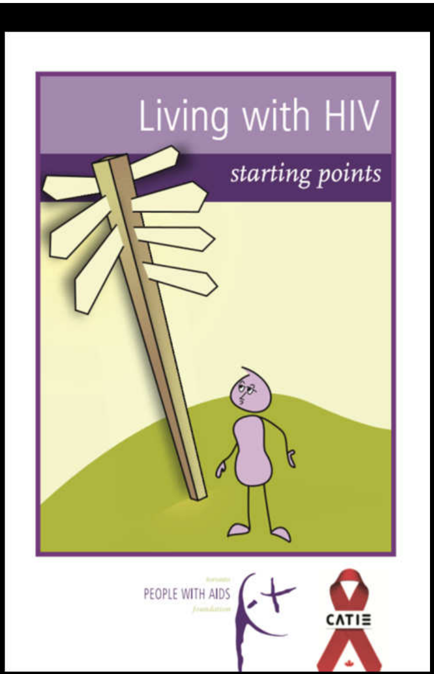
A cancer diagnosis has the power to produce a myriad of overwhelming emotional responses, including shock, denial, anxiety, fear, grief, and depression. A cancer patient's footpath through the health care system involves dealing with this host of feelings while juggling a multitude of medical tests and consultations to determine a definitive diagnosis and course of treatment. In addition, many patients do not fully appreciate the need for prompt access to care, which further confounds their situation. This pathway, to say the least, can be a confusing labyrinth.[1]

Cancer care is often complex, with many patients facing complicated treatment regimens, individualized therapies, and rapidly changing evidential recommendations for existing therapies. Patient navigators take some of this burden from the patient. They guide patients with cancer through complex treatments during a formidable time. Patient navigators are an important bridge between the doctor, adjunct services, and the patient.

4. ‘Living with’ guides

Alzheimer foreningen
Livet med demens

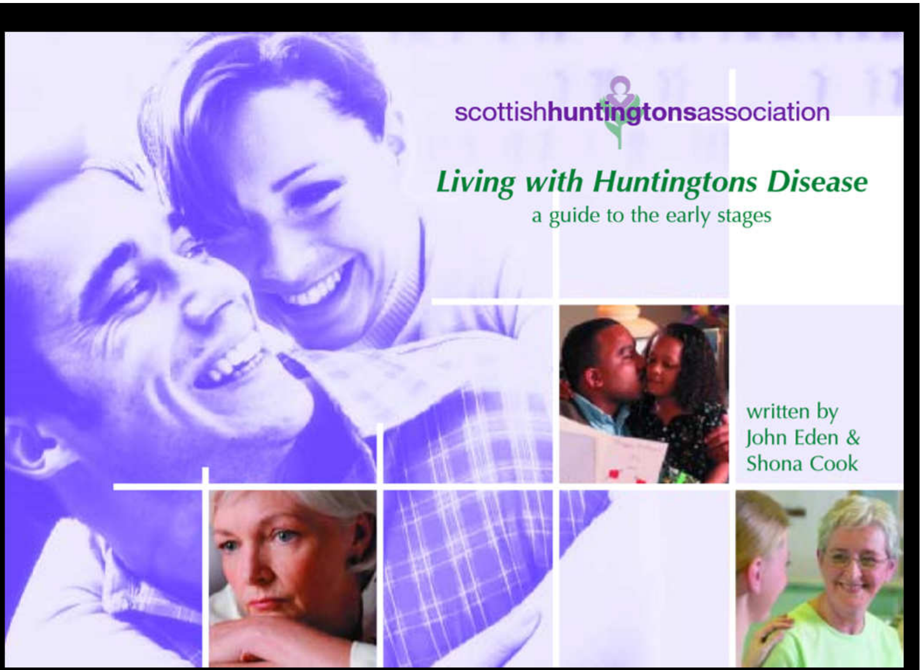
Lev
med demens



Living with HIV
starting points

toronto
PEOPLE WITH AIDS
foundation

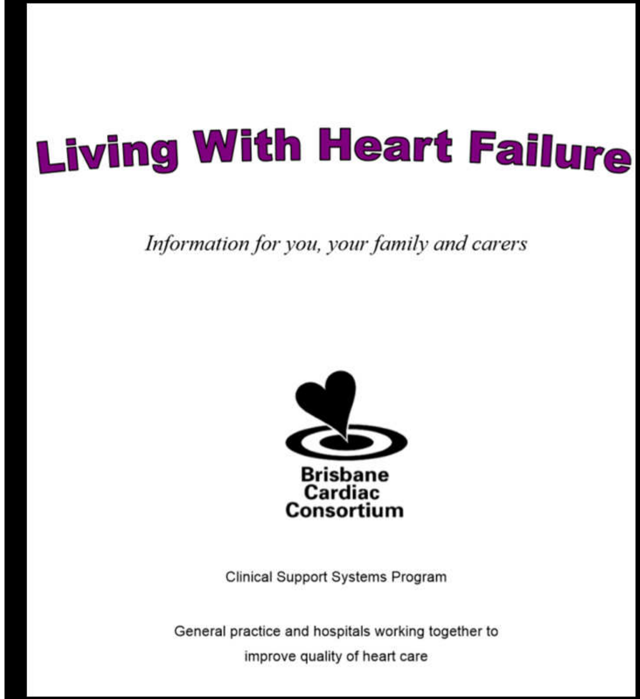
CATIE



scottishhuntingtonsassociation

Living with Huntingtons Disease
a guide to the early stages

written by
John Eden &
Shona Cook



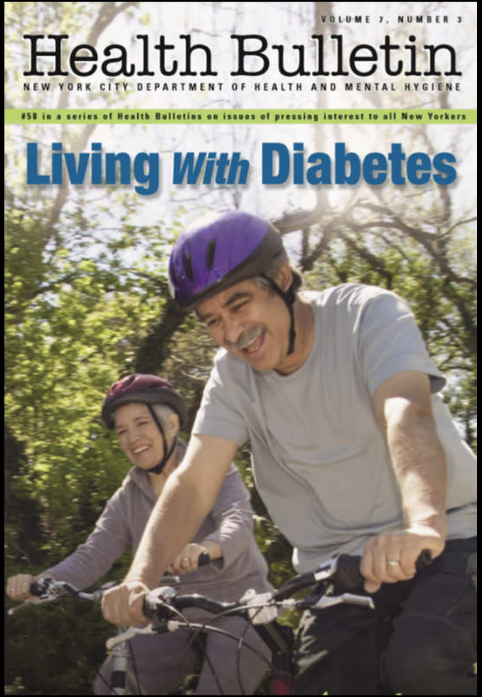
Living With Heart Failure

Information for you, your family and carers

Brisbane
Cardiac
Consortium

Clinical Support Systems Program

General practice and hospitals working together to
improve quality of heart care

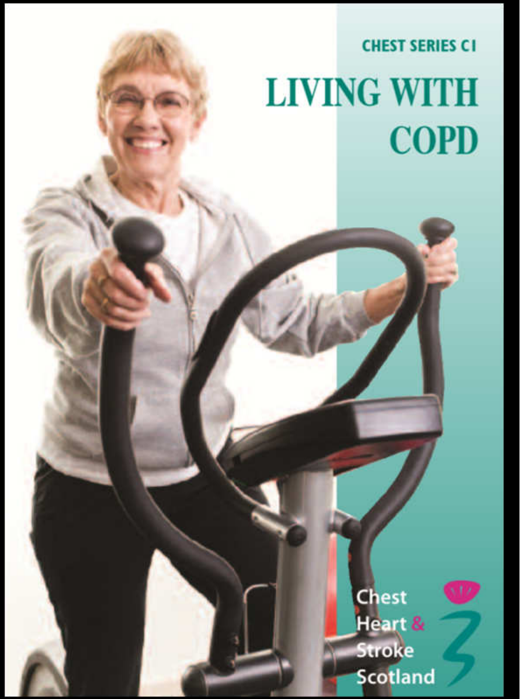


VOLUME 7, NUMBER 3

Health Bulletin
NEW YORK CITY DEPARTMENT OF HEALTH AND MENTAL HYGIENE

#58 in a series of Health Bulletins on issues of pressing interest to all New Yorkers

Living *With* Diabetes



CHEST SERIES C1

LIVING WITH
COPD

Chest
Heart &
Stroke
Scotland

“Life with Alzheimer’s is a shared concern for both the one who has the disease and her or his loved ones. Alzheimer’s infiltrates deep into family life. Roles transform and ways of being together change character. Hence, when a diagnosis has been given, the challenge is to find out **how you will live a life with Alzheimer’s together**… Whether you have Alzheimer’s or are a loved one, you will need good advice as well as help and guidance to the different phases that you will go through as the disease progresses.”

Living with dementia, Danish Alzheimer Association 2012

Aktive tilbud til mennesker med en demenssygdom

Alzheimerforeningen tilbyder hvert år højskoleophold og andre aktiviteter for mennesker med en demenssygdom. Se tilbud på www.alzheimer.dk eller ring til Alzheimerforeningen på 39 40 04 88.

SAMVÆR

Socialt samvær med andre har en positiv effekt på, hvordan mennesker med en demenssygdom lever med sygdommen. Brug derfor dine omgivelser. Forsøg at holde fast i din omgangskreds. Bevar de gode måder at være sammen med familie, venner og naboer på.

GØR HVERDAGEN LETTERE

Faste rutiner, enkle systemer og hjælpemidler kan skabe overskuelighed, tryghed og ro i din hverdag. Samtidig kan det hjælpe dig til at fortsætte hverdagen, som du kender den. Men efterhånden som sygdommen skrider frem, får du også behov for at ændre dine daglige rutiner eller indføre helt nye.

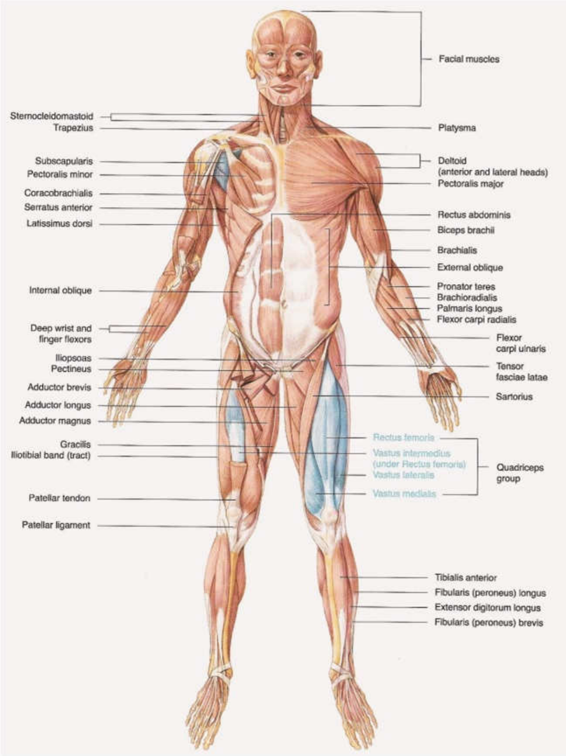
HJÆLP TIL AT HUSKE

Det kan være, at du på et tidspunkt får brug for hjælp til at huske at bruge dine hjælpemidler i hverdagen – for eksempel til at kigge i kalenderen eller se på ugeplanen.

Concluding thoughts

- Health care in the 21st century requires inter-disciplinary collaboration
- Prolonging life and improving life are equally important therapeutic objectives today
- Epidemiology, biomedicine, anthropology, psychology, and more are needed
- Each discipline has its strengths and limitations – methodologically, analytically

- Qualitative health research can generate systematic insights into more or less shared ways of thinking, doing or being
- This knowledge is just as translatable into health care practice as knowledge of cellular mechanisms, treatment effect, disease burden, lifestyle exposures, etc.
- What we need is clarity about research objects and good old-fashioned division of labour


Facial muscles
Sternocleidomastoid
Trapezius
Platysma
Subscapularis
Pectoralis minor
Coracobrachialis
Serratus anterior
Latissimus dorsi
Deltoid
(anterior and lateral heads)
Pectoralis major
Rectus abdominis
Biceps brachii
Brachialis
External oblique
Internal oblique
Pronator teres
Brachioradialis
Palmaris longus
Flexor carpi radialis
Deep wrist and
finger flexors
Flexor
carpi ulnaris
Iliopsoas
Pectineus
Tensor
fasciae latae
Adductor brevis
Sartorius
Adductor longus
Adductor magnus
Rectus femoris
Gracilis
Iliotibial band (tract)
Vastus intermedius
(under Rectus femoris)
Vastus lateralis
Vastus medialis
Quadriceps
group
Patellar tendon
Patellar ligament
Tibialis anterior
Fibularis (peroneus) longus
Extensor digitorum longus
Fibularis (peroneus) brevis


Niños
Adicciones
Trastornos límite de

Now that I have all this off my chest, I’m not so tired any more and I look forward to collaborating with you all!

thank you
tak
kiitos
谢谢
cảm ơn