Size and Burden of Mental Disorders and other Disorders of the Brain in Europe 2010

Hans-Ulrich Wittchen on behalf of the study group

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Our 2005 Report findings at a glance

- Every year, **27%** of the EU population suffer from mental disorders
- Exceedingly high degree of associated psychosocial impairments/disability
- Under-recognition, under-treatment, inadequate treatment
- Yearly cost burden mental disorders: 276,851 billion €; unlike other disease groups low direct (35%) vs high indirect (59%) costs
- Total 2004 costs of „disorders of the brain“ in Europe: 386,179 billion

Limitations of the 2005 Report - the need for improved data

- Restricted set of diagnoses (19 groups)
- No coverage of childhood/adolescence and the elderly
- Incomplete and outdated epidemiological, burden and cost data
- Coverage of the „old“ EU (plus Switzerland, Norway and Island) only
The Mission

Provide improved up-to-date data on the size, burden and cost
- of a more complete range of mental disorders and neurological disorders
- in the enlarged EU population of all ages
- retaining comparability with the previous 2005 study

Steering Board: Olesen, Jönsson, Wittchen

Epidemiological panels
- Size (12-month prevalence)
- Number of persons affected
- Associated diagnostic burden
- Treatment

Health economic panels
- Cost per case and diagnosis
- Country and EU total costs
- Country costs
- Cost modeling

Hundreds of expert advisors and consultants

Data analytic centres: Stockholm and Dresden

Literature search and analyses, reanalyses of original data, consensus rating, imputations and modeling
Process and methods

Steering Board

Epidemiological panels (for each group of disorders)

Task forces for reanalyses and validation

Epidemiological panels (for each group of disorders)

Steering Board & centre staff

Tasks
Selecting advisors
Constituting panels
Coordinating meetings
Supervising process
Aggregation
Statistics, modeling
Publication

Tasks
State of the art literature search
Conducting reanalyses of data
Extracting the 12-month estimates
Deciding on applicable age ranges
Health economic data
Country imputations & adjustments
Best estimates for prevalence and cost

Tasks
Country estimates
Cost data by diagnosis
Cost data by country
Aggregation & modeling
EU-estimate: size, burden
EU-estimate cost
Publication

General population data
  - For some countries and disorders

Community (e.g. subjects living in the community)
  - For many countries and disorders

High risk cohorts (e.g. with shared exposure or characteristics)

Subjects with current disorders (undiagnosed, untreated)
  - For some countries and many disorders referring to costs

Patients in treatment services (treated prevalence, e.g. primary care, specialist mental health services)

Clinical research settings

For some countries and many disorders referring to costs
What are mental disorders?
The term describes hundreds of mental and behavioral disorders treated by psychiatrists and other professionals in the mental health care sector. They are specified in the International Classification of Diseases (ICD-10, 10th revision) of the World Health Organization or the more research-oriented Diagnostic and Statistical Manual of Mental Disorders (DSM-IV, 4th revision).

Older synonyms for mental disorders are: mental illness/disease, psychiatric illness, neuropsychiatric disorders/illness more recent terms are MNS-disorders (mental, neurological and substance disorders);
These terms should not be confused with „psychological problems“ or „mental health problems“ which are no diagnostic terms and adress a wider range of problems.

What are neurological disorders?
The term describes hundreds of diseases of the Central Nervous System (CNS) including the brain as specified in ICD-10, typically diagnosed and treated by neurologists.

What are disorders of the brain?
A new term, reflecting that both groups of disorders are closely related, sharing overlapping causal mechanisms and common research and diagnostic strategies and treatments.
Mental and behavioural dis. (F00-G99)

- Mental retardation (F10.2)
- Hyperkinetic disorder/ADHD (F90.x)
- Conduct disorders (F91.x)
- Autism/pervasive developmental dis. (F84.x)
- Substance use disorders (alcohol, opiate and cannabis dependence (F10.2, F11.2, F12.2)
- Dementias (F00-F03)
- Schizophrenia, psychotic disorders (F2x)
- Mood disorders (Depression and Bipolar Disorders) (F32, F33, F30, F31)
- Anxiety disorders (e.g. Panic disorder, Generalized Anxiety disorder, Phobias) (F40x, F41x)
- Obsessive-compulsive disorders (F42)
- Trauma- and stress-related disorders (F43.1)
- Somatoform disorders (F45)
- Sleep disorders (i.e. insomnia) (F51x, G47)
- Eating disorders (F50.0, F50.1, F50.2, F50.3)
- Personality disorders (F60.2, F60.3)

Neurological disorders (G00-G99)

- Neuromuscular disorders (Muscular Dystrophies, Acquired Neuropathies, Autoimmune Disorders of muscle and of the neuromuscular junction)
  - Parkinson’s Disease (G22x)
  - Alzheimer’s dementia (G30x)
  - Multiple Sclerosis (G35x)
  - Epilepsy (G40x)
  - Migraine ((G43x), other headaches (G44x)
  - Stroke (G45x)
  - Traumatic brain injury (TBI) (GS00-S09)
  - Brain Tumours (malignant, benign, of unknown origin) (C70, C71, C72; D32, D33,; D42, D43)

Diagnostic coverage

Overall 31 mental and 62 neurological disorders grouped for the purposes of this report in 19 meaningful major diagnostic groups
Mental disorders
- mental and behavioural disorders ("psychiatric" disorders)
- Neurological disorders (and other CNS disorders)

Disorders of the Brain

Also Neuropsychiatric disorders or Mental, Neurologic, Substance disorders (MNS)

Challenges of combining mental and neurological disorders
- Comprehensive data collection and aggregation, reanalyses, modeling
- Disciplinary fragmentation (i.e. different traditions, methods and designs)
- Handling inconsistencies and the lack of missing data (i.e. for countries, comorbidity)
- Differences (diagnosis, treatment, health care structure, resources, quality of care)
- Variability in forms and expressions over the life span (different methodologies)
Results I: The size of mental disorders in Europe

Reanalyses of hundreds of epidemiological studies in the EU (1990-2010) taking into account general population, community and services (e.g. primary care) data as well as comorbidity findings to derive at „best-estimates“ for the 12-month* prevalence of disorders
Mental Disorders by best-estimate 12-month prevalence (%)

- Anxiety disorders
- Insomnia
- Unipolar depression
- Dementia
- ADHD/Hyperkin. dis.
- Somatoform disorders
- Alcohol dependence
- Conduct disorder
- OCD
- Psychotic disorder
- Personality dis.
- PTSD
- Mental retardation
- Opiate dependence

Subtypes of anxiety disorders
- GAD
- Specific phobia
- Social phobia
- Agoraphobia
- Panic disorder

Every year 38.2% of the EU-population suffers from a mental disorder

OCD: Obsessive-Compulsive Disorder
PTSD: Post-traumatic Stress Disorder
Somatoform without headache

Every year 38.2% of the EU-population suffers from a mental disorder.
How do these prevalence numbers translate into numbers of patients?
Mental Disorders by prevalence (and estimated number of persons affected in millions)

- OCD: 0.7 (2.9m)
- Eating disorder: 0.9 (1.5m)
- Cannabis dependence: 1.0 (1.4m)
- Psychotic disorder: 1.2 (5.0m)
- Personality dis.: 1.3 (4.3m)
- PTSD: 2.0 (7.7m)
- Conduct dis.: 4% in total (3.0 (2.1m))
- Alcohol dependence: 3.4 (14.6m)
- Somatoform disorders: 4.9 (20.4m)
- ADHD/Hypercin. dis.: 0.6% in total (5.0 (3.3m))
- Dementia: 1.2% in total (5.4 (6.3m))
- Unipolar depression: 6.9 (30.3m)
- Insomnia: 7.0 (29.1m)
- Anxiety disorders: 14.0 (29.1m)

Overall, 164.8 million people of the total EU population of 510 million are affected by mental disorders.

Many more by neurological disorders.

Neurological disorders: Number of persons (millions)

- Headache*: 54.10
- Sleep Apnoea: 12.50
- Stroke: 8.17
- Dementias**: 6.34
- Traumatic brain injury: 3.75
- Epilepsy: 2.64
- Parkinsons Disease: 1.18
- Multiple Sclerosis: 0.54
- Neuromuscular dis.: 0.26
- Brain Tumours: 0.24

*Overall, 164.8 million people of the total EU population of 510 million are affected by mental disorders.
**Many more by neurological disorders.
The „hit list“ of „disorders of the brain“ in numbers

<table>
<thead>
<tr>
<th>Diagnostic group</th>
<th>Estimated number of persons in million</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brain tumor</td>
<td>0.2</td>
</tr>
<tr>
<td>Neuromuscular disorders</td>
<td>0.3</td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>0.5</td>
</tr>
<tr>
<td>Parkinson's disease</td>
<td>1.2</td>
</tr>
<tr>
<td>Eating disorders</td>
<td>1.5</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>2.6</td>
</tr>
<tr>
<td>Traumatic brain injury (TBI)</td>
<td>3.7</td>
</tr>
<tr>
<td>Mental retardation</td>
<td>4.2</td>
</tr>
<tr>
<td>Personality disorders</td>
<td>4.4</td>
</tr>
<tr>
<td>Psychotic disorders</td>
<td>5.0</td>
</tr>
<tr>
<td>Child/Adolescent disorders</td>
<td>6.1</td>
</tr>
<tr>
<td>Dementias</td>
<td>6.20</td>
</tr>
<tr>
<td>Stroke</td>
<td>8.2</td>
</tr>
<tr>
<td>Addiction</td>
<td>15.5</td>
</tr>
<tr>
<td>Somatoform disorder</td>
<td>20.3</td>
</tr>
<tr>
<td>Mood disorders</td>
<td>33.3</td>
</tr>
<tr>
<td>Sleep disorders</td>
<td>44.7</td>
</tr>
<tr>
<td>Anxiety disorders</td>
<td>69.2</td>
</tr>
<tr>
<td>Headache</td>
<td>154.1</td>
</tr>
</tbody>
</table>

*estimated number of subjects*
ECNP/EBC Report on Size and Burden 2005 vs 2011: Did the prevalence of mental disorders change?

- **No** evidence for increasing or decreasing rates overall, when the same diagnoses are considered as in the 2005 report
  - Overall prevalence in 2005 report: 27.4% - in 2011 report: 27.1%
  - Slightly higher 2011 estimate for alcohol dependence (2.4% vs 3.4%, due to higher prevalence in eastern states) and for agoraphobia 1.3 vs 2.0%; diagnostic convention

- The inclusion of the new 2011 diagnoses add a further 11.1%

- Resulting in a new 2011 overall 12-month prevalence estimate of 38.2%:
  - PTSD, personality disorders, hyperkinetic disorders/ADHD, conduct disorder, autism, mental retardation, insomnia/other sleep disorders, dementias

Hence – *a much more comprehensive coverage and picture of disorders of the brain in Europe*
ECNP/EBC Report on Size and Burden 2005 vs 2011: Did the number of persons affected in the EU change?

- **Yes** – due to the larger EU reference population
  - 2005: EU reference population: 301.7 million (18-65 years of age),
  - 2011: EU reference population: 514 million (all ages)

- **Yes** – due to a larger number of diagnoses covered

  As a result of both effects, the estimated number of persons changed
  - From 82 million (out of 301 m) **persons in 2005**
  - To 164.8 million (out of 514 m) **in 2011**

- This is still a conservative estimate because:
  - Many disorders could not be included
  - Only cases meeting full diagnostic criteria are considered
Comparison of 2005 with 2011 report: Estimates for Prevalence (A) and number of patients affected (B) in the EU

12-month prevalence (%)

A

Additional disorders 2011
same diagnoses

38.2%

11,1

27.4

27.1

12-month prevalence 2005 Report
12-month prevalence 2011 report

No. Patients affected in million

B

Additional disorders 2011
same diagnoses

164.8

46.7

82.7

118.1

number persons affected 2005 Report
number persons affected 2011 report
Some findings in greater detail:

1. Children and adolescents are frequently affected
2. Child-adolescent ages are high risk periods for onset
3. Early onset has longterm implications
4. The type of disorders matters
5. Males and females are different
Mental disorders: frequently early onset

Childhood/adolescence
- Mental retardation
- Hyperkinetic dis./ADHD
- Conduct disorders
- Pervasive developm.dis.
- Phobias
- Anorexia nervosa
- Some epilepsies

Late adolescence
- Drug use disorders
- Panic, OCD, PTSD
- Mood disorders
- Somatoform disorders
- Schizophrenic dis.
- Bulimia nervosa
- Personality disorders.

Adulthood (ages 20-50)
- Alcohol dependence
- Depression
- Generalized Anxiety dis.
- Sleep disorders
- Multiple Sclerosis
- Traumatic brain injury
- Brain tumours
- Neuromuscular dis.

Later life
- Stroke
- Parkinson’s disease
- Dementias
- Sleep disorders
- Subthreshold anxiety and depression
  “multimorbidity”
Cumulative incidence risk of anxiety (AD), substance use and depressive disorders and critical trajectory “windows”

1st "window" AD
- Panic, phobias, OCD, PTSD
- CI (%)
- 1st onset almost invariably in childhood/adolescence
- Narrow "high risk of onset" window for most anxiety disorders: ages 5-28
- A smaller 2nd high risk window for late onset GAD and PD: 38-47
- Systematic differences by type of anxiety disorders

2nd “window” AD
- Late onset PD/GAD

Age of onset

Wittchen & Jacobi 2005, Beesdo et al 2010
12-month prevalence overall estimates do not inform about the age-specific risk for a disorder in males and females.

Cumulative hazard rate (%)

Incidence unipolar depression (onset of the first episode in life)

12-months prevalence (%) Major depression and Dystymia

Wittchen et al (2011)
### Gender differences: Overall prevalence is similar, but different diagnostic spectrums

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Female: Male Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental retardation</td>
<td>0.8</td>
</tr>
<tr>
<td>Opiate dependence</td>
<td>0.7</td>
</tr>
<tr>
<td>OCD</td>
<td>1.6</td>
</tr>
<tr>
<td>Eating disorder</td>
<td>6.2</td>
</tr>
<tr>
<td>Cannabis dependence</td>
<td>0.4</td>
</tr>
<tr>
<td>Psychotic disorder</td>
<td>0.8</td>
</tr>
<tr>
<td>Personality disorder</td>
<td>0.4</td>
</tr>
<tr>
<td>PTSD</td>
<td>3.4</td>
</tr>
<tr>
<td>Conduct disorder</td>
<td>0.3</td>
</tr>
<tr>
<td>Alcohol dependence</td>
<td>0.3</td>
</tr>
<tr>
<td>Somatoform disorders</td>
<td>2.1</td>
</tr>
<tr>
<td>ADHD/Hyperkinetic disorder</td>
<td>0.3</td>
</tr>
<tr>
<td>Dementia</td>
<td>1.6</td>
</tr>
<tr>
<td>Unipolar depression</td>
<td>2.3</td>
</tr>
<tr>
<td>Insomnia</td>
<td>2.0</td>
</tr>
<tr>
<td>Anxiety disorders</td>
<td>2.5</td>
</tr>
</tbody>
</table>

**Subtypes of anxiety disorders**

- GAD: 2.1
- Specific phobia: 2.4
- Social phobia: 2.0
- Agoraphobia: 3.1
- Panic disorder: 2.5
Findings in greater detail:

6. Comorbidity is frequent phenomenon and
7. has significant consequences and implications
72.2% of the mood disorders
54.3% of all anxiety disorders are comorbid
49.2% of the somatoform disorders
41.2% of substance use disorders

Cross-sectionally many cases with a mental disorder have more than one disorder - rates of comorbidity increase by age

A. Example: Proportion (%) of comorbid cases

B. Increase of comorbidity by age

Similar patterns also exist with other mental disorders as well as between neurological and mental disorders - Meaning and implications?
Two case examples for comorbid patterns over time

**Case 1: Female Age 18**
- **Mother:** Somatoform anxiety NOS, major depression
- **Father:** No dx

- 5-7 Enuresis
- 7-18 Sit. phobia
- 6-12 social fears; 12-20 Social Phobia, gen.
- 8 panic attack; 14-17 PD
- 15 MDE (7wks)
- 18 MDE ongoing

**Case 2: Male Age 19**
- **Mother:** MDE, panic dis., somat. dis.
- **Father:** Alcohol dep. nicotine dep.

- 2-6 sleep disturbance
- 10-19 animal phobia
- 12-19 social phobia
- 12 dysthymia, 17 MDE
- 16 alcohol dependence
Meaning and Implications of comorbidity

- **Random association** (i.e. having a flue and diabetes)
- **Expression of similar or overlapping risk factors** (i.e. anxiety and depression share similar dysfunctions in neurotransmitter processes)
- **One disorder is a risk factor for onset of another** (or reciprocal processes)

Consequences: greater severity and suffering, malignant course, psychosocial complications, poorer therapy response etc.
Early onset anxiety
Increasing fear liability

Social deficits

Increasing avoidance

social reinforcers, ↓

neg. reinforcement, ↑
social learning ↓

Occurrence in developmentally vulnerable phase

Fear, anx, avoidance
Reduction of:
- Social learning
- skills acquisition
- developm. milestone achievement
- competencies

Impairment/disability
- School
- career & work
- social network
- Higher-order cognitive functions

Demoralisation
- negative affect
- depression risk factors

Compensation
- Maladaptive choices
- substances

Escalation
- ↑ restrictions
- ↓ longterm disab.
- ↓ quality of life
- depression

Age/duration

Risk for secondary depression
5.6-fold increased risk
Depression is considered to occur in milder or very severe forms, often episodic (about 1/3), can be recurrent (1/3) or even chronic (1/3).

- Single episode
- Recurrent episodes
- Chronic

**Primary pure depression**
- 75% remit within 3 months (mean: 8 wks)
- 10 years episode risk: mean 1.8
- Acute impairment/disability: moderate (SDS: 6.2)
- Impairment/disability persists beyond the depressive episode: 2.3 months
- Academic, work failure, underperformance, unemployment rate: 29%
- Suicide attempts: 4.3%

**Secondary depression**
- 40% remit within 3 months (mean: 18 wks)
- 10 years episode risk: mean 1.9
- Acute impairment/disability: moderate to severe (SDS: 9.2)
- Impairment/disability persists often beyond the depressive episode: 6.4 months
- Academic, work failure, underperformance, unemployment rate: 49%
- Suicide attempts: 11.3%
Findings in greater detail:

8. Treatment provision is largely deficient

Even in the most advanced health care system only a fraction of all patients with mental disorder receive any care.
Treatment rates of mental disorders are extremely low! No indication of changes since 2005

- Only 14-36% (depending on country) of all mental disorders are in contact with professional health care service because of their condition (Wang et al WMH 2008)

- Only half of them receive minimally adequate treatment (highest for psychotic and eating disorders; 72%, 61%)

- Probability of contact and treatment increases by illness duration, comorbidity and severity
Why are disorders of the brain characterized by such high indirect costs? Only 50% of all 12-month cases receive “treatment”!

“Any treatment“ rates between countries vary from a low of 24% to a high of 51.6%

Primary care is the most frequent provider!

If treatment occurs, typically multiple providers

Grossly adequate = medication plus 4 visits or 6 sessions of psychotherapy
Among those with “treatment” the initiation of treatment is considerably delayed (WMH 2008)

Cumulative Lifetime Probability of Treatment Contact

- Panic disorder
- Generalized anxiety disorder
- Post-traumatic stress disorder

Years Since Onset of Disorder

Cumulative Lifetime Probability of Treatment Contact

0 0.1 0.2 0.3 0.4 0.5 0.6 0.7 0.8 0.9 1.0

0 10 20 30 40 50 60 70 80
Delayed treatment: Proportional treatment contact in the year of onset for mood disorders and median duration of delay in cases with subsequent contact

<table>
<thead>
<tr>
<th>Country</th>
<th>Proportion %</th>
<th>MD delay in years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spain</td>
<td>48.5</td>
<td>1.0</td>
</tr>
<tr>
<td>Netherlands</td>
<td>52.1</td>
<td>3.0</td>
</tr>
<tr>
<td>Italy</td>
<td>28.8</td>
<td>2.0</td>
</tr>
<tr>
<td>Israel</td>
<td>31.9</td>
<td>6.0</td>
</tr>
<tr>
<td>Germany</td>
<td>40.4</td>
<td>2.0</td>
</tr>
<tr>
<td>France</td>
<td>42.7</td>
<td>1.0</td>
</tr>
<tr>
<td>Belgium</td>
<td>47.8</td>
<td>1.0</td>
</tr>
</tbody>
</table>
The treatment situation for mental disorders is deficient

Despite the existence of pharmacological and psychological treatments that are effective, treatment provision is highly deficient in the EU

- Among all 12-month cases with mental disorders the majority receives no “treatment”!
  - Only 30-52% (by country) had contact with any health professional
  - Only 8-16% (by country) with the mental health specialty sector
  - Only 2-9% has received minimally adequate treatment
    - drug tx >1 month plus > 4+ visits OR psychotherapy >8 sessions
    - mostly drugs, psychological treatments rarely provided (0-3% of all affected)
    - Considerable treatment delays after onset: MD: 15.6 years

- This situation of undertreatment, delayed and poor treatment is unique to mental disorders

- The situation for neurological disorders is significantly better for most diagnostic groups considered
Summary I: The size of mental and neurological disorders

- Every year, 38% of the total EU-population (≈164.7 m patients annually) suffer from at least one of the mental disorders
- Conservative estimate (e.g. incomplete diagnostic coverage, only threshold cases)
- Similarly high prevalence rates in all age groups in males and females
- Most frequent diagnoses (differ by gender): anxiety disorders, unipolar depression, insomnia, somatoform and substance use disorders
- As compared to our 2005-Report no evidence for
  - for changing rates or
  - improved treatment rates (despite all efforts still only 10% are treated!)
- The true size of „disorders of the brain“ including neurological disorders is considerably higher (no estimate provided due to lack of data on comorbidity)
Summary II: Disorders of the brain are the core challenge of the 21st century

• Disorders of the brain are impairing and disabling

• The frequent and high degree of impairment and disability can be directly linked to deficient treatment provision in EU

• Report 2005: Unlike other diseases, mental disorders are costly because of high indirect costs – and NOT because of direct treatment costs
  • E.g. medication costs account for less than 10% of the total cost burden

• Can we reduce the indirect cost burden by increasing direct costs?

• Challenges (Meeting the higher demand for healthcare; adapt health systems to the needs of an ageing population while keeping them sustainable)

• Need for improved models for intervention research and service provision
Conclusion III: Disorders of the brain – There are differences that matter

• Although all „disorders of the brain“, share many features, there are noteworthy differences between mental and neurologic disorders:
  
  • Highly prevalent mental disorders frequently start early, adversely impacting the person’s development over the whole life span, most prevalent neurological disorders start late (Dementias, Parkinson’s)
  
  • Highly deficient treatment provision is a unique finding for most mental disorders and not similarly frequent for neurological disorders
  
  • Treatment provision for mental disorders involves several professions (psychiatrists, GP, psychologists, etc) using different models, methods and procedures
  
  • The majority of treatments provided for mental disorders do not match treatment guidelines. Screening campaigns might be irrelevant unless minimal standards of adequacy are met.
Recommendations for political action

- Mental disorders must become high priority in the EU
- Existing programmes initiatives must be strengthened and broadened
- Research emphasis: Causes and developmental pathways, improved drug and psychological treatments, targeted prevention and improved models of allocation of scarce resources to mental disorders
- Industry and investors must be encouraged and supported to engage in disorder of the brain research as the core health challenge of the future
- Curricula and training of all health professions need to cover disorders of the brain and their appropriate treatment
- National policies should adopt a “disorders of brain” agenda ensuring unrestricted access to treatment to contain the immense societal costs
- Funding for basic, clinical and public health research must be drastically increased to reflect appropriately the true size and burden
European programatic research funding for disorders of the brain is low in relation to the true size and burden.

Relevance for the public, policy makers and researchers

- To increase awareness about the spectrum of disorders of the brain and their "true" size, burden and cost in the society
- To make disorders of the brain a priority in research and health policies
- To correct prevailing misconceptions (i.e. only few are affected, personal weakness, mental disorders cannot be treated or prevented effectively)
- To reduce stigma
- To inform about
  - research deficits
  - Specific needs by diagnosis
  - By country

Coming up in the October issue
Results II
The burden of mental disorders and disorders of the brain in Europe

Jürgen Rehm on behalf of the study group

Institute of Clinical Psychology und Psychotherapy
Center of Clinical Epidemiology and Longitudinal Studies (CELOS)
Technische Universität Dresden, Germany

and

Centre for Addiction and Mental Health,
Toronto, Canada
Results II:
The burden of mental disorders and disorders of the brain in Europe

What is new?

- More diagnoses covered
- First time ever, data specifically for the EU (Inclusion of new EU membership states (plus Norway, Switzerland, Iceland)
- First time ever, burden calculated based on country data and separately for males and females and by age group
- Specific estimates for Disability Adjusted Life Years Lost (DALY) and Years Lived with Disability (YLDs)
Burden is a complex concept with different connotations

- Patient burden (e.g. suffering of symptoms, social role restriction, reaction by others)
- Caregiver burden (e.g. partner/family, distress, guilt, everyday life, financial burden)
- Treatment system burden (e.g. emotional, time, logistical burden, referral)
- Society/social policy: (e.g. health care, psychosocial, economic, DALY)

- Health economic and cost burden
  - Direct health care costs (e.g. hospital, medication costs, therapists costs)
  - Indirect costs (e.g. work days lost, work productivity lost, life years lost to premature mortality, DALYs but only is tranposed into $ metric)
  - Social costs (direct; e.g. providing sheltered work settings or accomodation)
  - Other direct costs (e.g. legal costs: police, court, prisons)
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- Health economic and cost burden
  - Direct health care costs (e.g. hospital, medication costs, therapists costs)
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  - Social costs (direct; e.g. providing sheltered work settings or accommodation)
  - Other direct costs (e.g. legal costs: police, court, prisons)
Complexity and interaction of burden

- Patients’ suffering & Burden
- Family & Social network
- Course and outcome of illness
- Health care system characteristics
- Health care professionals´ burden
- Social policy characteristics

Further factors:
- Stigma, guilt and self-blame
- Time of onset in life span
- Severity and stage of disease
- Availability of treatments
- Regional/national variability (e.g., health care system, social policy characteristics)

The course, outcome and impact on burden depends heavily on the interplay of these factors

Societal and health economic burden
An example: DALY Calculation
(the easiest way based on 1990 GBD v. 1996)

Years of life lost to premature mortality (YLLs)

Years lost to disability (YLDs)

Inputs
• Age at death
• Life expectancy at age of death (conditional life expectancy)

Inputs
• Age at occurrence (incidence)
• Duration of disease/injury
• Disability weight of disease/injury

DALYs are a summary measure for the gap to perfect health until the best life expectancy possible (currently the Japanese).

They combine years of life lost to premature mortality and years of life lived with suboptimal health (= years lived with disability)
DALY calculation: an example

A Two-Car Collision

<table>
<thead>
<tr>
<th>1 family dies</th>
<th>2 people injured</th>
</tr>
</thead>
<tbody>
<tr>
<td>- 10 year old girl</td>
<td>- 45 y/o woman – spinal cord</td>
</tr>
<tr>
<td>- 8 year old boy</td>
<td>injury</td>
</tr>
<tr>
<td>- 38 year old mother</td>
<td>- 55 y/o man – fractured rib</td>
</tr>
<tr>
<td>- 42 year old father</td>
<td></td>
</tr>
</tbody>
</table>

**YLLs from deaths**

- 73 year life expectancy
- 72 year life expectancy
- 45 year life expectancy
- 39 year life expectancy

**YLDs from injuries**

- duration (39 year LE) * disability wt (.725) = 28.275 YLDs
- duration (.115 years) * disability wt (.199) = 0.023 YLDs

\[ 229 \text{ YLLs} + 28.30 \text{ YLDs} = 257.30 \text{ DALYs} \]
Overall, so far there had been no calculation yet for the EU.

The WHO has their own categories such as Europe A, B, and C, which do not coincide with EU.

So we took the country data and combined them to a new calculation for the EU.
Revised 2011 DALY estimates for disorders of Brain: Males

Total rate per 10,000 DALYs:
- mental disorders: 280.0
- neurological: 66.1
- other: 21.0
Total neuropsychiatric: 367.1

Equals 23.4% of the all cause morbidity burden in males

Proportion of neuropsychiatric DALYs of all disease groups:
- Mental dis. 5.6
- Neurological 1.3
- Other 0.4
- Other disease groups 31.6
Revised 2011 DALY estimates for disorders of Brain: Females

Total rate per 10,000 DALYs:
- mental disorders: 298.8
- neurological: 66.9
- other: 17.8
Total neuropsychiatric: 293.5

Equals 30.1% of the all cause morbidity burden in females

Proportion of neuropsychiatric DALYs of all disease groups
Revised 2011 DALY estimates: Gender comparison

### Males:
- Total neuropsychiatric: 23.4%
  - Mental dis.
    - PTSD: 5.6
    - Neurological: 1.3
    - Other: 0.4
  - Neurological: 31.6
  - Other disease groups: 28.125

### Females:
- Total neuropsychiatric: 30.1%
  - Mental dis.
    - PTSD: 6.43
    - Neurological: 1.655
    - Other: 0.383
  - Neurological: 31.6
  - Other disease groups: 28.125

DALY Rate per 10,000 persons
Depression: The disability burden is not equally distributed

Prevalence by age and gender

<table>
<thead>
<tr>
<th>Age group</th>
<th>Males</th>
<th>Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;15</td>
<td>1.9</td>
<td>2.3</td>
</tr>
<tr>
<td>15-25</td>
<td>6.4</td>
<td>6.8</td>
</tr>
<tr>
<td>26-35</td>
<td>10.5</td>
<td>13.4</td>
</tr>
<tr>
<td>36-45</td>
<td>13.4</td>
<td>12.5</td>
</tr>
<tr>
<td>46-55</td>
<td>5.8</td>
<td>6.1</td>
</tr>
<tr>
<td>56-65</td>
<td>5.4</td>
<td>5.4</td>
</tr>
<tr>
<td>66+</td>
<td>3.8</td>
<td>6.9</td>
</tr>
</tbody>
</table>

In proportions (%) of all cause DALYS

Age group

<table>
<thead>
<tr>
<th>Males</th>
<th>Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4</td>
<td>0</td>
</tr>
<tr>
<td>5-14</td>
<td>9.2</td>
</tr>
<tr>
<td>15-29</td>
<td>6.7</td>
</tr>
<tr>
<td>30-44</td>
<td>16.7</td>
</tr>
<tr>
<td>45-59</td>
<td>19.2</td>
</tr>
<tr>
<td>50-69</td>
<td>9.8</td>
</tr>
<tr>
<td>70-79</td>
<td>3.5</td>
</tr>
<tr>
<td>80+</td>
<td>0.4</td>
</tr>
</tbody>
</table>

ECNP/EBC Report 2011 on the Burden of disorders of the brain: What is new?

- More diagnoses covered
- First time ever data specifically for the EU
  - Inclusion of new EU membership states (plus Norway, Switzerland, Iceland)
- For the first time, burden was calculated based on country data
- Specific estimates for YLDs

Hence – a much more comprehensive coverage and picture of the DALY burden of disorders of the brain in Europe
<table>
<thead>
<tr>
<th>Neuropsychiatric Disorders</th>
<th>Total YLDs (15+ yrs)</th>
<th>Rate per 10,000</th>
<th>Rank</th>
<th>Neuropsychiatric disorders</th>
<th>Total YLDs (15+ yrs)</th>
<th>Rate per 10,000</th>
<th>Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>U086 Alcohol use disorders</td>
<td>1,486,800</td>
<td>73.8</td>
<td>1</td>
<td>U082 Unipolar depressive disorders</td>
<td>2,887,172</td>
<td>134.1</td>
<td>1</td>
</tr>
<tr>
<td>U082 Unipolar depressive disorders</td>
<td>1,424,813</td>
<td>70.7</td>
<td>2</td>
<td>U087 Alzheimer’s disease and other</td>
<td>1,265,040</td>
<td>58.8</td>
<td>2</td>
</tr>
<tr>
<td>U087 Alzheimer’s disease and other</td>
<td>636,355</td>
<td>31.6</td>
<td>3</td>
<td>U095 Migraine</td>
<td>490,744</td>
<td>22.8</td>
<td>3</td>
</tr>
<tr>
<td>U090 Drug use disorders</td>
<td>490,391</td>
<td>24.3</td>
<td>4</td>
<td>U083 Bipolar affective disorder</td>
<td>359,462</td>
<td>16.7</td>
<td>4</td>
</tr>
<tr>
<td>U083 Bipolar affective disorder</td>
<td>367,000</td>
<td>18.2</td>
<td>5</td>
<td>U086 Alcohol use disorders</td>
<td>330,314</td>
<td>15.3</td>
<td>5</td>
</tr>
<tr>
<td>U084 Schizophrenia</td>
<td>324,031</td>
<td>16.1</td>
<td>6</td>
<td>U084 Schizophrenia</td>
<td>302,757</td>
<td>14.1</td>
<td>6</td>
</tr>
<tr>
<td>U108 Stroke</td>
<td>206,777</td>
<td>10.3</td>
<td>7</td>
<td>U093 Panic disorder</td>
<td>256,932</td>
<td>11.9</td>
<td>7</td>
</tr>
<tr>
<td>U094 Insomnia (primary)</td>
<td>168,845</td>
<td>8.4</td>
<td>8</td>
<td>U094 Insomnia (primary)</td>
<td>220,908</td>
<td>10.3</td>
<td>8</td>
</tr>
<tr>
<td>U095 Migraine</td>
<td>151,933</td>
<td>7.5</td>
<td>9</td>
<td>U108 Stroke</td>
<td>187,130</td>
<td>8.7</td>
<td>9</td>
</tr>
<tr>
<td>U092 Obsessive-compulsive disorder</td>
<td>147,907</td>
<td>7.3</td>
<td>10</td>
<td>U092 Obsessive-compulsive disorder</td>
<td>181,777</td>
<td>8.4</td>
<td>10</td>
</tr>
<tr>
<td>U088 Parkinson’s disease</td>
<td>127,177</td>
<td>6.3</td>
<td>11</td>
<td>U091 Post-traumatic stress disorder</td>
<td>181,409</td>
<td>8.4</td>
<td>11</td>
</tr>
<tr>
<td>U093 Panic disorder</td>
<td>126,851</td>
<td>6.3</td>
<td>12</td>
<td>U090 Drug use disorders</td>
<td>160,637</td>
<td>7.5</td>
<td>12</td>
</tr>
<tr>
<td>U085 Epilepsy</td>
<td>75,245</td>
<td>3.7</td>
<td>13</td>
<td>U088 Parkinson’s disease</td>
<td>121,681</td>
<td>5.7</td>
<td>13</td>
</tr>
<tr>
<td>U091 Post-traumatic stress disorder</td>
<td>64,002</td>
<td>3.2</td>
<td>14</td>
<td>U085 Epilepsy</td>
<td>75,591</td>
<td>3.5</td>
<td>14</td>
</tr>
<tr>
<td>U089 Multiple sclerosis</td>
<td>49,347</td>
<td>2.4</td>
<td>15</td>
<td>U089 Multiple sclerosis</td>
<td>62,022</td>
<td>2.9</td>
<td>15</td>
</tr>
</tbody>
</table>
Overall, disorders of the brain are more disabling than fatal

- They are responsible for more than 42% of all the YLDs (years of life lost due to disability) in Europe.
- Many of these disorders are chronic relapsing diseases with a more and more chronic trajectory.
- Their disability weights are relatively high.
- High overall disability compared with relatively high incidence results in high YLDs.
The prevalence data used to estimate the burden are not the same as those used in our prevalence data. However, these data have been subjected to a consistency check in DISMOD, which compares current knowledge on prevalence, incidence, duration and case fatality to derive consistent estimates.

The disability weights are based on expert opinions and might thus not reflect the appropriately the EU empirical findings. However, the correlation between the European Disability Weight Project and the WHO weights used are very high. In addition, the new disability weights from general population samples are highly correlated with the expert ratings. However, there may be differences between countries which cannot be taken into account.

Two worlds: Epidemiological standards of community surveys are different from those in clinical samples (over- and underestimation).
Conclusion

- Disorders of the brain are prevalent (164.8 million of the total 510 million EU population for mental disorders alone, plus neurological disorders)

- Disorders of the brain are disabling (42% of all YLDs in the EU are caused by disorders of the brain)

- Overall, disorders of the brain cause the highest proportion of disease burden of all disease groups (Men 23%, women 30%)

- Europe has to act to reduce this burden by a) better prevention, b) better personalized treatment, and c) better treatment systems
Results

The 2010 cost of mental disorders and disorders of the brain in Europe
Figure X. Total cost by disorder and type of cost (€PPP million, 2010), all disorders
Figure X. Distribution of cost by disorder, the proportions of three types of costs as a share of the total stratified by disorder.
Figure X. Cost per subject by type of costs (€PPP 2010), all disorders

- Headache
- Eating disorders
- Sleep disorders
- Somatoform disorder
- Anxiety disorders
- Mood disorders
- Child/Adolescent disorders
- Addiction
- Epilepsy
- Personality disorders
- Stroke
- Trauma
- Intellectual disability
- Parkinsons disease
- Dementia
- Psychotic disorders
- Multiple sclerosis
- Neuromuscular disorders
- Brain tumor

Legend:
- Direct healthcare costs
- Direct non-medical costs
- Indirect costs
Figure X. Distribution of cost by mental disorders, the proportions of three types of costs as a share of the total stratified by disorder.
Figure X. Distribution of cost by neurological disorder, the proportions of three types of costs as a share of the total stratified by disorder.

- **Stroke**
- **Sleep disorders**
- **Parkinson's disease**
- **Epilepsy**
- **Multiple sclerosis**
- **Trauma**
- **Brain tumor**
- **Neuromuscular disorders**
- **Headache**
- **Dementia**

**Legend:**
- Direct costs
- Direct non-medical costs
- Indirect costs
The total distribution of the total direct medical, direct non-medical and indirect costs for disorders of the brain and by mental and neurological disorders.
Anxiety is characterized by high indirect and low direct costs.

Indirect costs: 69.4%

Direct treatment costs: 30.6%
- Psychotherapy 1.8%
- Drugs 2.3%

Andlin-Sobocki et al 2005, Wittchen & Jacobi 2011
Why are disorders of the brain characterized by such high indirect costs? Only 50% of all 12-month cases receive “treatment”!

„Any treatment“ rates between countries vary from a low of 24% to a high of 51.6%

Primary care is in all countries the most frequent provider!

If treatment occurs, typically multiple providers

Grossly adequate = medication plus 4 visits or 6 sessions of psychotherapy

ECNP-Task Force Report 2005: Size and burden of Mental Disorders in the EU

Wittchen & Jacobi 2005
Distribution of disorders of the brain are markedly different from other treatable diseases: A comparison

The cost burden of depression and other mental disorders is mainly determined by indirect costs!

This contrasts sharply to the situation for prevalent somatic diseases

Would an increase of direct costs for better and timely treatment reduce indirect costs and the overall cost burden?
Is the health economic burden increasing?

- Countries with currently few resources will increase expenditures.
- Increasing health expectancy – patients with mental disorder will live longer – thus extending possibly treatment periods.
- Increase of mental disorders in the elderly.
- Increase of treatment rates (childhood and adolescence, depression and anxiety).
- Offset effects (fewer indirect costs by higher direct)?

**Are the direct cost high?**

Over 32% of the total morbidity burden is due to disorders of the brain –

Versus 7% of the health care expenditure!

**Increase of direct costs – reduction of indirect costs?**

If yes what type of direct costs expenditures will be most effective?
In the EU and most Western countries – there is evidence for increased rates of depression since the 70ies

- Consistent evidence for increased depression rates in successively higher incidence in young cohorts
  - E.g. subjects born after 1934 have twice the risk, those born after 1964 almost three times the risk for MDE

- Age of onset for 1st episode has been decreasing

- Increases due to higher incidence of comorbid secondary depression

- Little evidence for artefacts (criteria, willingness to admit sx, etc)

- Effects are weakening though in younger cohorts

- Situation in the elderly (65+) remains unclear!

Wittchen et al 2010, Medicographica)
Did we fail so far to reduce the burden, because treatments are unavailable, difficult, ineffective and expensive?

• Not true!
  • effective treatments exist – despite the apparent need of improved therapeutic options
  • Treatments are increasingly acceptable to the public and patients
  • Treatment delivery is not difficult – given appropriate training, cost effectiveness is robustly established
  • The burden has increased at a slower pace than the incidence and prevalence for most disorders

• However, there is still tremendous room for improvement!
  • Providing proactive and earlier diagnosis and treatment
  • Designing and providing improved targeted treatments

• Concerted action - better models of service provision and research strategies
How can the size and burden of disorders of the brain be reduced?

- Reducing the size and burden within a coordinated public health effort
  - 1. Preventing the occurrence of new cases (primary prevention)
  - 2. Preventing recurrence risk and chronicity
  - 3. Preventing secondary comorbid disorders
  - 4. Slowing down the disease progression
  - 5. Reducing the associated psychosocial impairment/disability
- Except for primary prevention, effective (though imperfect) drug and non-drug interventions to reach these goals partially are established
- However these options are not yet exploited, particularly for mental disorders
- *We need improved treatments by investing lots of funds and effort into the research about the causes of these disorders and the development of novel treatments*
Challenges of determining the size and burden

- When does a disorder start? What are the high incidence risk phases of a disorder?
- How is the onset (insidious-slow, acute rapid etc)?
- What are the associated impairment and disabilities?
- What is the natural course (episodic/recurrent, fluctuating, progressive, chronic)?
- What are associated risks and complications of the natural course?
- Relationship among each other - comorbidity: aetiologic (unique and shared vulnerabilities and risk factors, moderator and mediator effects, symptom progression models)?
- Are they preventable - are they treatable? (assumed effect on size and burden)
- Are they recognized, diagnosed and treated? (actual effect on size and burden)

There is a need to describe the size and burden:
- by diagnosis (e.g. panic disorder)
- by diagnostic group (e.g. any anxiety disorder)
- and by „caseness“ (e.g. having any disorder)
Has the size of mental and neurological disorders increased since 1980?

Will it increase further?

Is the burden increasing?
Prevalence of mental disorders – increasing, decreasing, stable?

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Total</th>
<th>Sex</th>
<th>Time/Region*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementias</td>
<td>+++</td>
<td>F&gt;M</td>
<td>?</td>
</tr>
<tr>
<td>Parkinson’s Disease</td>
<td>+</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td>Somatoform disorders</td>
<td>+</td>
<td>F&gt;M</td>
<td>+</td>
</tr>
<tr>
<td>PTSD (ACS)</td>
<td>+/-/-</td>
<td>?</td>
<td>+</td>
</tr>
<tr>
<td>OCD</td>
<td>=</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Alcohol dependence</td>
<td>=</td>
<td>-</td>
<td>?</td>
</tr>
<tr>
<td>Nicotine dependence</td>
<td>+/-</td>
<td>F&gt;M</td>
<td>?, na</td>
</tr>
<tr>
<td>Drug dependence</td>
<td>+/-/=</td>
<td>F&gt;M</td>
<td>?, +</td>
</tr>
<tr>
<td>Psychotic disorders</td>
<td>=</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Anxiety disorders</td>
<td>=</td>
<td>=</td>
<td>?</td>
</tr>
<tr>
<td>Depressive disorders</td>
<td>++</td>
<td>F &amp; M</td>
<td>?</td>
</tr>
</tbody>
</table>

* Regional effects: Somatoform disorders in regions with dense health care structures, drug abuse

Except for depression and dementia no increase of prevalence!
In the EU, firm evidence for increased rates of depression: BUT no evidence of an epidemic!

- Evidence for increased depression rates in young cohorts
  - E.g. subjects born after 1934 have twice the risk, those born after 1964 almost three times the risk for MDE
  - Age of onset for 1st episode has been decreasing
  - Increase in recurrence risk in young cohorts
  - Evidence for longer duration of episodes in older subjects

- Increases due to higher incidence of comorbid secondary depression
  - Increase among young adults with primary anxiety, somatoform stress disorder
  - Increase due to an aging population (comorbid depression-somatic disease, in the elderly neurodegenerative diseases, higher chronicity risk in the elderly)

- The depression increase is larger (3:1) than the burden increase, so we were partially successful!

Would an increase of direct costs/better allocation decrease the indirect costs? What type of expenditures will be most effective?

Wittchen et al 2010, Medicographica)