

The choice of outcome parameters
and need for distinct assessment
tools with regard to the different
disease stages in Alzheimer's
disease...

Iva Holmerová

Czech Alzheimer Society
Alzheimer Europe

Patient organisation view

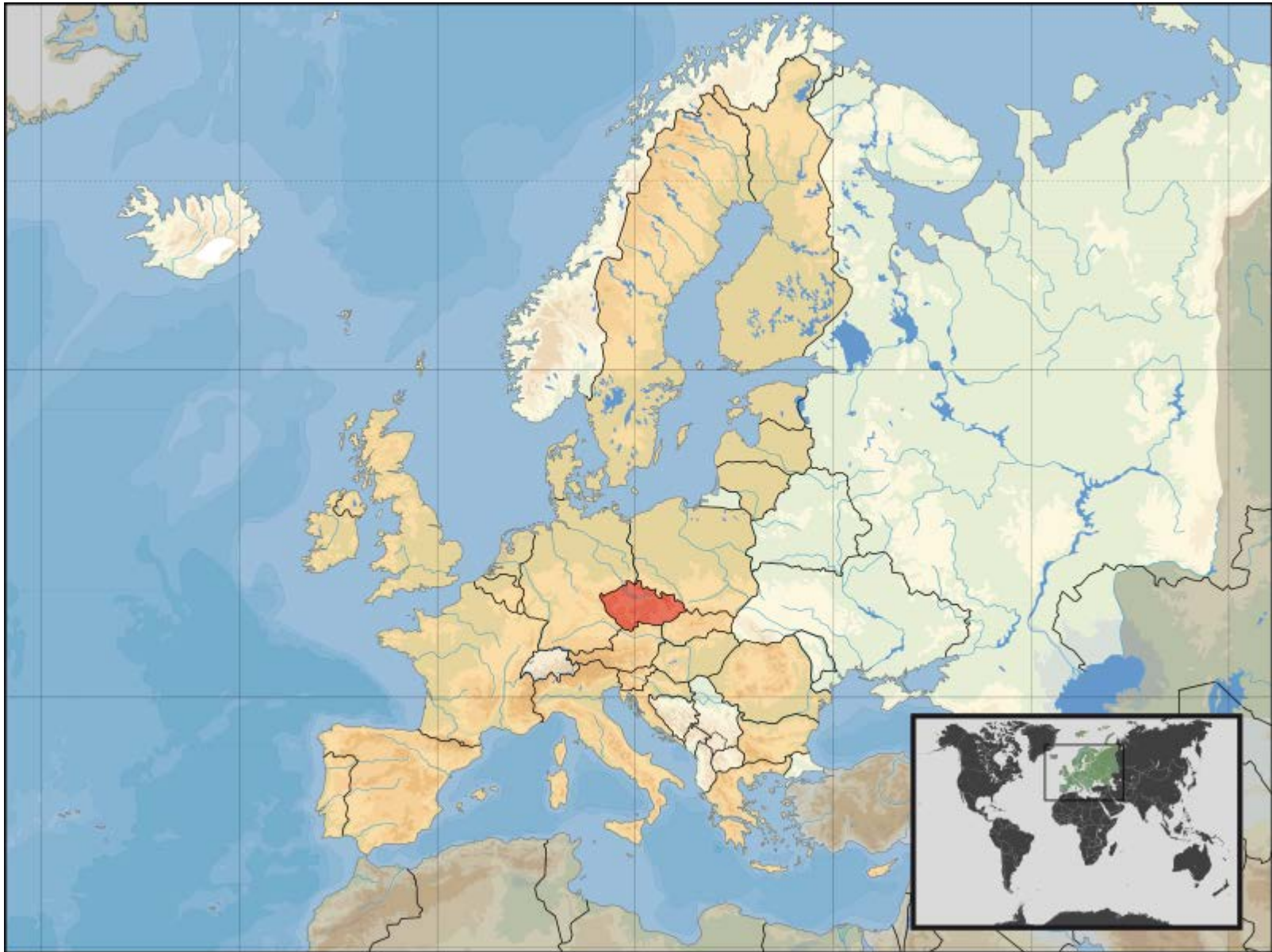


Czech Alzheimer Society



Alzheimer Europe





Czech Republic (since 1993)



- Population 10,5 mil. (6 % foreigners)
- Life Expectancy (males 75,2, females 81,1)
- Unemployment 7,4 % (end of July 2014)
- Economic growth 2,7% (2nd Q of 2014)
- Spending on health (7,5% of GDP)
- 140 ths. persons living with dementia



OSKAR FISCHER

1876- 1942

(Slaný - KZ Teresienstadt)

Worked in the Department of Pathology, Psychiatric Department, Charles University in Prague

1907 – pathological findings in 12 cases of „senile“dementia and 16 controls

Oskar Fischer's article

Fischer, Miliare Nekrosen mit drusigen Wucherungen etc. 361

Monatschrift
für
Psychiatrie und Neurologie.

Herausgegeben von

Th. Ziehen.

Band XXII.

Mit zahlreichen Abbildungen im Text und 5 Tafeln.



BERLIN 1907.
VERLAG VON S. KARGER
KARLSTRASSE 29.

(Aus der deutschen psychiatrischen Klinik [Prof. Dr. A. Pick] in Prag.)

Miliare Nekrosen mit drusigen Wucherungen der Neurofibrillen, eine regelmässige Veränderung der Hirnrinde bei seniler Demenz.¹⁾

Vorläufige Mitteilung von

Priv.-Doz. Dr. OSKAR FISCHER,

II. Assistenten der Klinik.

Im 17. Band der Jahrbücher für Psychiatrie und Neurologie beschrieb *Redlich* in der Hirnrinde von 2 Fällen seniler Demenz eine eigenartige Veränderung, die er miliare Sklerose nannte. Die Hirnrinde war übersät von mit Carmin intensiv sich färbenden Plaques von der Grösse einer Ganglienzelle bis zum 4–6fachen, die zwar diffus verstreut waren, am reichhaltigsten aber in der Schichte der kleinen Pyramiden sasssen. Im Zentrum zeigten sie homogenes, leicht körniges Gefüge, „während in der Peripherie noch ein feiner Faserfilz nachweisbar war, der einen allmählichen Uebergang bildete zur umgebenden Gliasubstanz“;

Disease burden

H.Brodaty (Paris Alzheimer, 2008):

- 19th century – infections
- 20th century – cardiovascular and oncological diseases
- 21st century – neurodegeneration

And yet: 1/20 of research support compared to oncological or cardiovascular diseases

DEMENTIA- Research focus on:

- Primary prevention
- Disease modification

Pre-clinical stages:

GAP between the precise diagnosis and no causal or d.m. therapy

Drug trials – hope to those (brave) who decide to know more

Ethical considerations (surveillance) and research, culture, anthropology...

- Symptomatic improvement
- „Stand alone“ (?) symptoms (agitation, aggression...)

ABC - Dementia syndrome

- Activities of Daily Living
- BPSD
- Cognition

Strategy P-PA-IA – acronym of three stages and changing needs of PwD *(strategy of the Czech Alzheimer Society)*



1 (P)

Psychology
Support
Counselling
Diagnosis
Disclosure
Therapy
Legal issues

2 (PA)

Meaningful activities
Care
Support
Caregivers
Supervision

3 (IA)

Individualized
approach
Nursing care
Palliative care

Complexity of the dementia syndrome

- Life history, experience,
- Values, priorities
- Current tasks of life

- Disease pathology (proteins – A-beta, tau)
- Localisation of pathology
- Different leading symptoms – h.memory, visuospatial, verbal, frontal ...
- Progression of the disease

- Environment and support, people around us, complexity of the external and changing world
- Different cultures....
- „psychosocial context“ and interventions

Dementia stage of AD research focus:

- Cognitive endpoint (objective tests)
- Functional endpoint (IADLs)
- Global endpoint (global assessment)
- other? – separate and integrated

- BPSD as „stand alone“
- ??? – resistiveness to care (Volicer)

Psychosocial interventions

Positive effects are demonstrated on patient

- cognition (Olazaran et al.,2010)
- behaviour (Olazaran et al.,2010)
- family carer mood (Vernooij-Dassen, Draskovic, et al., 2011)
- they reduce costs by delaying institutionalization (Spijker et al., 2008).



Clinical „pictures“ - complexity

- Different types of dementia
- Different manifestations of Alzheimer´s disease
- Variability: personality, context and conditions, disease progression....
- Do we need more appropriate and detailed descriptions of „clinical pictures“ of dementia? Follow up along the progression trajectory?
- Dementia as a „novel“ syndrome (20th century...)

- God is in the detail (A. Warburg)
- Morelli case in art (C. Ginzburg)

Suggestions:

- Ethical considerations – on a higher level than currently
- Anthropological issues/cultural differences
- Social aspects – stigma, occupation, insurance...
- Effects of psychosocial aspects and interventions
- Context of life, care and therapy...

Should be considered also in drug trials

Is it possible to separate drug, clinical and psychosocial research on dementia?



CELLO - *Centrum pro studium dlouhověkosti a dlouhodobé péče*
Fakulta humanitních studií Univerzity Karlovy
Gerontologické centrum
18200 Praha 8 – Kobylisy
Šimůnkova 1600
email: iva.holmerova@gerontocentrum.cz
www.cello-ilc.cz