Dementia: European Social Care Perspectives

Döbler, Joachim; Judd, Dawn B.

Empfohlene Zitierung / Suggested Citation:
Döbler, J., & Judd, D. B. (2014). Dementia: European Social Care Perspectives. In J. Döbler, & D. B. Judd (Eds.), *Dementia: European Social Care Perspectives* (pp. 15-58)Ostfalia University of Applied Sciences. https://nbn-resolving.org/urn:nbn:de:0168-ssoar-60435-4

Ambulante Betreuung hilfs- und pflegebedürftiger Menschen e.V.
Braunschweig

ambet

Dementia

European Social Care Perspectives

Edited by:
Joachim Döbler and Dawn B. Judd

Ostfalia
University of
Applied Sciences
Wolfenbüttel, January 2014

Dementia – European Social Care Perspectives

Publishers: Ostfalia - University of Applied Sciences
Institute for Legal and Social Studies
Am Exer 6
38302 Wolfenbüttel
http://www.ostfalia.de/cms/de/s/IRS/index.html

Ambulante Betreuung hilfs- und pflegebedürftiger
Menschen e.V. Braunschweig (ambet e.V.)
Triftweg 73
38118 Braunschweig
http://www.ambet.de

Editors: Joachim Döbler, Dawn B. Judd

Cover Photo: Klaus G. Kohn
http://www.klaus-g-kohn.com

Layout: Joachim Döbler
http://www.doebler-online.de

Print: LASERscript, Braunschweig

ISBN 978-3-00-044055-7

Acknowledgements

We would like to thank all of the contributors in this edited collection for their work. The authors are part of a growing international movement who are committed to developing a wider understanding of dementia and the associated needs of those with the various conditions that fall under the broad umbrella of this diagnosis. As can be seen from the various contributions in this edited collection, this needs to also embrace an understanding of the demands and situations of those caring for people with dementia. In an increasingly globalised world this book aims to provide a comparative understanding of the delivery and organization of dementia services in various European states. We have brought together academics and practitioners from various parts of Europe and from a range of disciplines to contribute to this book. The nature of an edited collection implicates that a range of views, styles and theoretical approaches have to be included. This is reflected in the diversity of the language used and the analysis that the authors have adopted. It is hoped that the contributions will be used to stimulate discussion and add to the debates linked to this important area.

We would particularly like to thank John Parkinson who has provided much appreciated help with editing. Funding provided by the Ostfalia, University of Applied Sciences, Faculty of Social Work is gratefully acknowledged.

Joachim Döbler
Dawn B. Judd

Table of Contents

Dementia: European Social Care Perspectives

Joachim Döbler and Dawn B. Judd

Ageing Europe

Europe is ageing! Its citizens are now increasingly entering their 'fourth age' (Laslett 1991; Baltes 1998) within an 'extended life course' (Imhof 1987). The demographic revolution can be seen as a ubiquitous process that is changing the conditions and structures of social integration and reproduction. These changes – interacting with the challenges of modernization – are affecting the cultural, social, economic and political dynamics of all European societies.

Images of ageing and old age are dynamic, above all they are social constructions and concepts that are highly dependent on cultural change, economic resources and political decisions. In modern societies social and individual configurations are linked to the triumphant advances of science and welfare. To this end biological processes and traditional turning points now emerge as less relevant for establishing the 'age' of people. Instead of this traditional orientation it is increasingly the continuity of life which follow on from the pathways and options of middle adulthood that become more and more important in the trajectory of old age.

Based on processes of expansion and differentiation, society offers a remarkable set of options for designing one's later life. Of course, the options for 'one's own life' (Beck and Beck-Gernsheim 2002) are dependent on wider social factors. More controversially, this raises the need to now critically question how far the concepts of ageism and social exclusion can be generally applied to adequately describe the living conditions of all old people. In particular this needs to be explored in relation to those who are ageing comfortably, i.e. they are well-off, competent, in relative good health and meeting the ideal of 'extra years' (Imhof 1981). Factors which provide the conditions, not only for an individual's 'successful ageing' (Havighurst 1961; Baltes and Baltes 1993), but also for their social engagement (Haski-Leventhal 2009). However, in acknowledging social and individual configurations it becomes obvious that both dimensions – the (self)-evaluation of being ‘old’ and the allocation of resources for a good and active life in old age – have to be seen as a result of multi-factorial constraints, structures and decisions.

The concept of ‘Active Aging’ which was developed by the World Health Organization can be defined as a “process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age“ (WHO 2002a, p.12). This includes not only those who are enjoying the options and benefits of their third age but also those who have crossed the line from third to ‘fourth age’. It is this group which is most often confronted with the challenges of frailty and dependency. Increasing longevity means taking into account the fact that a growing number of people are and will be in need of (long term) care and support. Critical views on the future of European welfare systems, the structural changes in family systems and the sustainability of intergenerational solidarity provide ample reasons to be concerned about the quality of support (inclusion) and the social acceptance (integration) of people as they enter the last stage of their life. Frailty and dependency threaten the concepts of ‘self-determination’ and ‘responsibility’ which are deeply rooted in modern society and the concept of the ‘enabling state’.

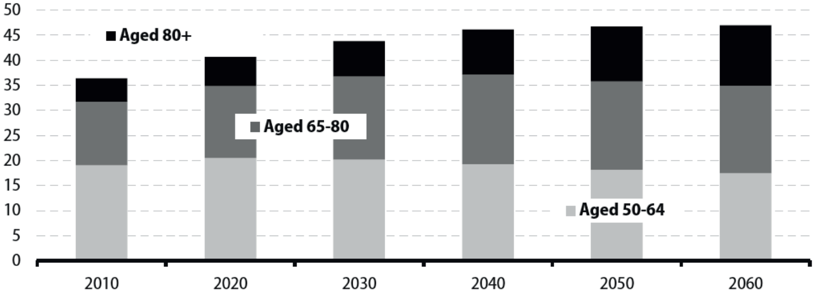
Demographic Transitions

Concentrating on the details of demographic developments as outlined in the World Alzheimer Report 2013, the demographic transition is proceeding particularly rapidly in low and middle income countries – significantly faster than was previously the case in the ‘old world’. As the Alzheimer’s Disease International (ADI) World Report 2013 highlights, “the transition from 7% of the total population aged 65 years and over, to 14% took 115 years in France (1865-1980), 69 years in the USA (1944-2013), and 45 years in the United Kingdom (1930-1975). The same transition will be accomplished in just 21 years in Brazil (2011-2032), 23 years in Sri Lanka (2004-2027) and 26 years in China (2000-2026)” (ADI 2013, p. 13).

In Europe there is a need to acknowledge that the EU-27 are undergoing significant demographic changes: one of which is an ageing population. From 1960 to 1980 the median age of EU Member States' populations remained fairly unchanged. "Thereafter, the EU's population started to age at a relatively rapid pace. (…) Eurostat population projections (…) suggest that the pace at which the median age is growing will abate somewhat in the coming decades" (Eurostat EU COM 2011, p. 16):

Figure 1: EU-27 – Projected structure of the population by age group and year (% Share of the total population)

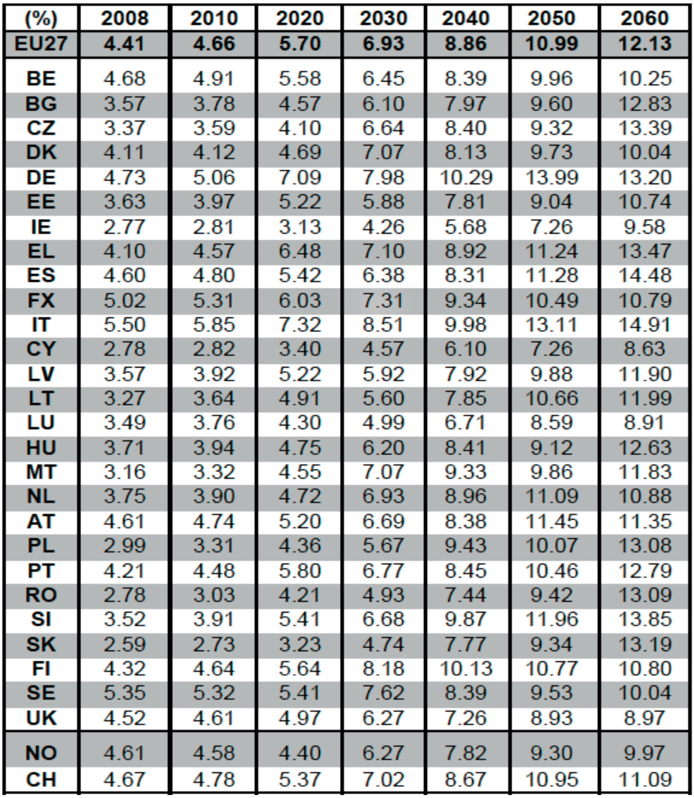
(Source: Eurostat EU COM 2011, p. 32)



- During the period 1990 to 2010 the percentage of people aged 65 or over in the total population rose from 3.7% to 17.4%. As Eurostat comments "There was particularly rapid growth in Slovenia, Germany, Italy, the Baltic Member States and Greece, as the share of those aged 65 or over in the total population increased by at least five percentage points." (Eurostat EU COM 2011, p. 19)
- According to The International Longevity Centre (ILC 2011) the EU-27 population will become older with the median age projected to rise from 40,9 years in 2010 to 47.9 years in 2060. If current trends continue, then the over 65s in the EU will increase from 85 million in 2008 to 151 million by 2060. The share of people aged 65 years or over in the total population is thus projected to increase from 17.1% to 30.0%.

- Demographic ageing is projected to increase in all countries, but according to the Eurostat Demography Report 2010 “The EU population ages at varying speed. Populations that are currently the oldest, such as Germany‘s and Italy‘s, will age rapidly for the next twenty years, then stabilise. Some populations that are currently younger, mainly in the East of the EU, will undergo ageing at increasing speed and by 2060 will have the oldest populations in the EU” (Eurostat EU COM 2011, p. 21). In the future there will be significant differences not only between the EU member countries but also between European regions – especially those that are affected by patterns of economic migration.

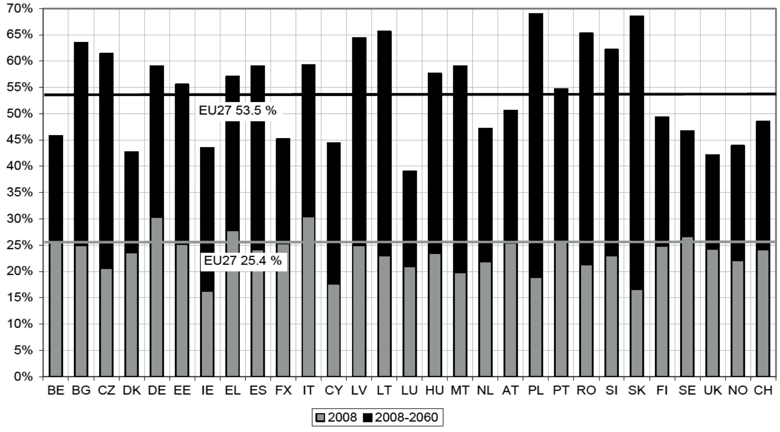
Table 1: Share of the total population aged 80 years or over
(Source: Eurostat Europop, cited in: Eurostat EU COM 2008, p.10)



(%)	2008	2010	2020	2030	2040	2050	2060
EU27	**4.41**	**4.66**	**5.70**	**6.93**	**8.86**	**10.99**	**12.13**
BE	4.68	4.91	5.58	6.45	8.39	9.96	10.25
BG	3.57	3.78	4.57	6.10	7.97	9.60	12.83
CZ	3.37	3.59	4.10	6.64	8.40	9.32	13.39
DK	4.11	4.12	4.69	7.07	8.13	9.73	10.04
DE	4.73	5.06	7.09	7.98	10.29	13.99	13.20
EE	3.63	3.97	5.22	5.88	7.81	9.04	10.74
IE	2.77	2.81	3.13	4.26	5.68	7.26	9.58
EL	4.10	4.57	6.48	7.10	8.92	11.24	13.47
ES	4.60	4.80	5.42	6.38	8.31	11.28	14.48
FX	5.02	5.31	6.03	7.31	9.34	10.49	10.79
IT	5.50	5.85	7.32	8.51	9.98	13.11	14.91
CY	2.78	2.82	3.40	4.57	6.10	7.26	8.63
LV	3.57	3.92	5.22	5.92	7.92	9.88	11.90
LT	3.27	3.64	4.91	5.60	7.85	10.66	11.99
LU	3.49	3.76	4.30	4.99	6.71	8.59	8.91
HU	3.71	3.94	4.75	6.20	8.41	9.12	12.63
MT	3.16	3.32	4.55	7.07	9.33	9.86	11.83
NL	3.75	3.90	4.72	6.93	8.96	11.09	10.88
AT	4.61	4.74	5.20	6.69	8.38	11.45	11.35
PL	2.99	3.31	4.36	5.67	9.43	10.07	13.08
PT	4.21	4.48	5.80	6.77	8.45	10.46	12.79
RO	2.78	3.03	4.21	4.93	7.44	9.42	13.09
SI	3.52	3.91	5.41	6.68	9.87	11.96	13.85
SK	2.59	2.73	3.23	4.74	7.77	9.34	13.19
FI	4.32	4.64	5.64	8.18	10.13	10.77	10.80
SE	5.35	5.32	5.41	7.62	8.39	9.53	10.04
UK	4.52	4.61	4.97	6.27	7.26	8.93	8.97
NO	4.61	4.58	4.40	6.27	7.82	9.30	9.97
CH	4.67	4.78	5.37	7.02	8.67	10.95	11.09

- In all EU-27 Member States women live longer than men; but the gender gap varies substantially between countries. In 2009, the gender gap in life expectancy at birth varied from under five years in the UK, Denmark, Sweden, Greece, Malta and the Netherlands to more than ten years in the Baltic States (Eurostat EU COM 2010). Following the 2012 Ageing Report "Life expectancy at birth for males is projected to increase by 7.9 years over the projection period, from 76.7 in 2010 to 84.6 in 2060. Life expectancy at birth is projected to increase by 6.5 years for females, from 82.5 in 2008 to 89.1 in 2060, implying a slight convergence of life expectancy between males and females" (COM 2011, p. 18).
- The population of the oldest old (aged 80 years or over) is projected to increase in relative, as well as, absolute terms for all countries. Eurostat (Eurostat EU COM 2008) suggests that the number of people aged 80 years or over is projected to almost triple from 21.8 million in 2008 to 61.4 million in 2060. By 2060 all European countries will have to address the needs of growing numbers of people aged 80 years or over forming an estimated 9% -15% of the total population.

Figure 2: Old age dependency ratio for the EU-27 Member States, Norway and Switzerland: 2008/2060
(Source: Eurostat EU COM 2008, p. 4)



- The result of age differences in the working age populations combined with the general increase of the population aged 65 years or over, means that the old-age dependency ratio (the population aged 65 or over in relation to that aged 20-64) ranges across the EU Member States from 17.8% in Slovakia to 31.6% in Italy. Eurostat (2008) suggests that over the projection period 2008 to 2060, the old age dependency ratio for the EU-27 is projected to more than double from 25.4 % in 2010 to 53.5 % in 2060.
- A more precise description and future orientated projection of these shifts in the prevalence of dependency can be taken from a four-country survey (Germany, Spain, Italy, UK) that was published by the London School of Economics in 2003. According to this research “The percentage of older people (aged 65 and older) with one or more ADLs in Spain and Italy (14% and 15% respectively) are similar to the percentage of older people with two or more ADLs in the United Kingdom (15%)“ (Rothgang and Comas-Herrera 2003, p. 165). The dependency prevalence increases for people aged 85+ to more than 40%. In all age groups the prevalence is markedly higher for women than for men.
- The future development of dependency is highly controversial and contested. The EU Demography Report in 2010 suggests that in general “The number of years spent in self perceived good health has been increasing in most of the countries studied (…) The evidence about the severity of disabilities in old age is mixed, especially for individuals over the age 85: whereas some severe disabilities appear to be declining, some less severe forms of disability and certain illnesses seem to be increasing, although this may be due to earlier diagnosis and greater life expectancy” (Eurostat EU COM 2010, p. 39). With respect to the gender gap Oeppen and Vaupel (2002) note that men have a lower life expectancy than women, but a higher proportion of their remaining life expectancy is spent in relatively good health.
- According to Rothgang and Comas-Herrera (2003), the question of old age dependency (which is linked to the future development of morbidity and disability) can be discussed using four scenarios:

A) A rise in healthy life expectancy with a constant number of years spent in bad health
B) A rise in healthy life expectancy with fewer years spent in bad health (compression of morbidity)
C) Additional years of life spent in poor health (expansion of morbidity)
D) Additional years with a higher a risk of dependency for a share of older people and a decrease of age-specific morbidity for the majority (bi-modality of morbidity).

Dementia and Alzheimer's Disease

While many older people are now living longer and healthier lives, across Europe dementia in its various forms affects significant numbers of older people. Dementia describes a variety of neurological disorders that progressively lead to brain damage and cause a gradual deterioration of the individual‘s cognitive capacity and social functioning. It is one of the most marked causes of impairment among elderly people, generating many practical and emotional challenges not only for those with the condition but also for their carers. Readers familiar with the disease will be all too aware of its trajectory: one of slow decline with variable rates of individual progression, impact and course but always ultimately leading to death. Generally the clinical symptoms of dementia usually begin after the age of 60, and the prevalence increases markedly with age.

To this end dementia has been described as an umbrella term that describes "not actually a disease but rather a set of symptoms" (Alzheimer Europe 2008, p. 19), in other words: an "acquired syndrome of decline in memory and other cognitive functions", which occurs when the brain is affected by certain diseases or conditions. As recognised in the World Alzheimer Report 2009, clinical correlation studies indicate that mixed pathologies are much more common than 'pure dementia'. Several types of dementia may be distinguished: inter alia vascular dementia, dementia with Lewy bodies, Parkinson, fronto-temporal dementia, Korsakoff's syndrome and HIV-related cognitive impairment. Germany‘s national

Public Health Institute, the Robert Koch Institute (Weyerer 2005) categorises the umbrella term “dementia” into five disease patterns:

- Neuro-degenerative dementia (for example Alzheimer)
- Vascular dementia (for example multi-infarct dementia)
- Dementia caused by substances with a toxic or metabolic action (for example alcohol)
- Dementia caused by a chronic inflammatory disease (for example HIV)
- Dementia caused by traumatic brain injury.

The most common form of dementia is Alzheimer’s Disease (AD), first described by the German neurologist Alois Alzheimer in 1906, which is responsible for 60% to 80% of dementia cases. This is the fourth most common cause of disease in high-income countries (ADI 2009). Notably many people with the condition go un-diagnosed. While presently there is no treatment that can cure dementia, the use of medication and other interventions can alleviate the symptoms especially in the early stages. AD is a progressive disease, which not only causes a cognitive deterioration but also substantial changes of emotional stability and social behaviour. Described as the “gradual deterioration of people’s functional capacity” it has a clear social dimension as it changes people’s “roles, responsibilities and social relations. All these changes and losses affect the person’s identity and sense of self.” (Alzheimer Europe 2008, p. 19)

The progression of AD can be classified in three stages: mild, moderate and severe. “It is associated with a decline in brain function over time and patients have an average life expectancy of 7-10 years after diagnosis” (Alzheimer Europe 2006, p. 3). As demonstrated in Table 2, AD in its early stage results in short term memory loss, difficulty in making decisions and difficulty recognising time, dates and surroundings. As dementia progresses, people may have speech problems, become easily disoriented, have disturbed sleep and develop ‘difficult’ and ‘challenging’ social behaviours (Halek and Bartholomeyczik 2006). Galasko et al (1997) have outlined how the person becomes more and more unable to perform the activities of daily living. In the later stages of dementia, a person may also have problems in eating and communicating, finally becoming completely dependent on social and nursing care (ILC 2011).

Table 2: Progression of Alzheimer's Disease

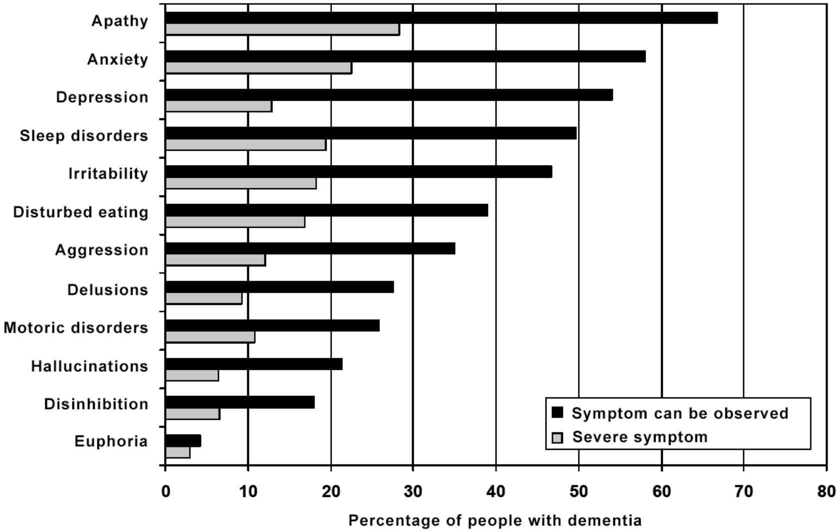
	Mild Stage	Moderate Stage	Severe Stage
Decline: Cognitive dimension	Short term memory losses, difficulties in concentrating / in orientation, becomes lost in familiar places. Repetitive questioning	Loss of ability to make judgements / to perform complex social interaction: Aphasia	Loss of ability to speak. Does not recognise familiar objects
Individual reactions / strategies	Irritation, mood swings, feelings of anxiety. Use of strategies to hide or compensate losses. Social withdrawal. Disengagement	Affective changes. Incapable of self-perceiving. Cognitive disorders. Aggression	Screaming. Agitation. Immobility
Challenges: Social dimension	Inability to perform in complex tasks. Withdrawal from threatening tasks. Attention & night time disturbance	Behavioural problems. Difficulty with day-to-day living. Wandering. Becomes lost at home and outside. Inappropriate behaviour in public. Dependent on caregivers	Incontinence. Eating difficulties. Fails to recognise relatives and friends. Dependent on others for basic needs. Behavioural disorders including physical violence
Support	In need of assistance	Requires assistance in performing activities of daily living (ADL). In need of care	Complete dependence on nursing care. Confined to a wheel chair or bed
Life expectancy	>> 7 to 10 years (after diagnosis) >>		

In fact AD is much more than the loss of memory. It is a "progressive neuro-degenerative disease, causing deterioration in all areas of mental ability, accompanied by changes in behaviour and personality. Symptoms of AD include inability to perform previously routine and daily tasks (function), impaired memory (cognition), difficulty with language, including remembering or finding words (communication), as well as personality and mood changes such as agitation and aggression (behaviour)" (Alzheimer Europe 2006, p. 3).

While clinicians focus their diagnostic assessments on impairment in cognitive functions, family and professional carers have to deal with the behavioural and psychological symptoms. It is these that are most relevant in the social relationships that care is imbedded in. According to Alzheimer's Disease International "Around one quarter of people with dementia exhibit apathy and a similar proportion show occasional signs of aggression. Common psychological symptoms include anxiety, depression, delusions and hallucinations. Around 25-40% have diagnosable affective disorder, and at least 10% have psychotic symptoms. The frequency and profile of these symptoms seems to be similar between developed and developing country settings" (ADI 2009, p. 6). A recent study by the Alzheimer's Society UK (2013a) suggests 1 in 5 people with dementia experience severe depression and related psychiatric symptoms. This publication examines how depression and anxiety, albeit often unrecognised, can affect people with dementia. It also suggests ways to provide appropriate support and looks at how depression and anxiety can be treated through a range of mediums and approaches.

Similarly the German representative study about providing care for people with dementia in private households, which was published by Schneekloth and Wahl (Schäufele et al 2005), notes a high psychiatric comorbidity of depressiveness and mild dementia. Based on the definition of 12 different disorders the study also investigated the appearance of psychiatric symptoms (figure 3). It reported that 93.6% of all people suffering from dementia had shown at least one of the 12 defined symptoms within the previous four weeks before being questioned. The numbers of symptoms were seen to rise with the increasing severity of the disease: on average 3.6 psychiatric symptoms were seen in the mild stage of dementia, rising to 4.5 symptoms in the moderate stage and 5.8 symptoms in the severe stage. Agitated and disturbed behaviour, empirically recorded using the modified Cohen-Mansfield (1996) Agitation Inventory (mCMAI-K), was assessed in 58% of all those examined.

Figure 3: Frequency of neuro-psychiatric symptoms
(Source: Schäufele, Köhler, Teufel, Weyerer 2005, p.108
{translation by the authors})



The representative findings from Germany showed that impairments in the 'activities of daily living' (ADL) and 'instrumental activities of daily living' (IADL) (Lawton and Brody 1969) grow rapidly with the severity of the AD. Schäufele et al (2005, p. 113) provide evidence of how all areas are affected including showering and washing, dressing, mobility and preserving continence as well as housekeeping and domestic tasks. 82% of the people suffering from moderate dementia and 100% of the people suffering from severe dementia were not able to enjoy bathing independently. 88% of the people suffering from moderate dementia and nearly all of those with severe dementia were in need of assistance when dressing. 61% of them had completely lost control over their bladder function.

In taking a more detailed look at the IADL, then significant difficulties emerge. People with AD loose their ability to carry out routine daily activities including dressing, undressing, using the lavatory, travelling and handling money. As a result, many require a high level of care. Taking a more in-depth view of the results of the German study on the impact of dementia/AD, then no one with a severe dementia diagnosis and only a few of those with a diagnosis of ‘moderate dementia’ were able to independently do housework, to move outside of their own homes, take responsibility for their own medication or make complex decisions (i.e. handle finances). The steadily growing inability to remain alone for more than several hours indicated the growing need for care, assistance and supervision, which is the reality of the so-called “36-Hours Day”. This was a term used by family carers to describe their experiences in the research undertaken by Mace and Rabins (2001). In other words: “AD can have a catastrophic impact. As the disease progresses patients change from being healthy, autonomous members of society to being completely dependent on others, both physically and mentally” (Alzheimer Europe 2006, p. 3).

Generally as summarised by the European Research Agenda (ILC 2011): “Dementia/AD is considered to be among the most disabling of all chronic diseases. The middle to late stages of the disease, in particular, signal a loss of autonomy, physical and cognitive function and independence for most individuals affected” (ILC 2011, p. 11). As AD progresses, people become more and more dependent on assistance and support and finally on long term care. As such, AD affects many other people, especially relatives and others in the person’s family system, but it is – as to be shown – also a challenge for the welfare state, social services departments and their employees. Several studies which focus the challenges that family carers have to deal with emphasise that they can live with cognitive deficits of their relatives, but that the behavioural and mood-related symptoms are much more difficult to handle. The psychological symptoms and associated disturbances in behaviour that most commonly occur in the later stages of the disease emerge as especially troublesome. They are an important cause of strain on carers and, as the family’s coping reserves become exhausted, often result in people moving from home care to a nursing home (Agüero-Torres et al 2001; Alzheimer Scotland 2007).

Comparative research findings analysed by the Harvard School of Public Health and Alzheimer Europe (Harvard School 2011) found that while dementia is commonly associated with disability and cognitive impairment, it is rarely recognised as a fatal disease that leads to death. According to WHO 2005 “The dementia specific mortality rate has been found to be twice the rate of people without dementia, controlling for co-morbidities and socio-demographic factors” (cited. in ILC 2011, p. 12). In the UK, it has been estimated that the proportion of deaths attributable to dementia increases steadily from 2% at age 65 to 18% at age 85-89 in men, and from 1% at age 65 to 23% at age 85-89 in women (Knapp and Prince 2007).

Conceptualizing Dementia

Actual discourses on and investigations into dementia and Alzheimer’s Disease and its impact on individuals, families and health and social care system (ADI 2010) have to be seen as part of a far-reaching and long lasting ‘epidemiologic transition’. The complexity of the disease makes treating dementia extremely difficult. Across Europe this involves a wide variety of social and health care services who are drawing on a range of interventions and approaches to staff training. While accepting that in early stages of the disease some of the symptoms can be arrested, there are no effective health care treatments for ‘curing’ dementia. This sense of incurability can produce a mindset of irretrievable loss, tragedy and helplessness that is often reflected in the care systems available to those with dementia. Good practice in this field, as advocated by various national and international dementia organizations, suggests that only by adopting social and person-centred (Kitwood 1997) practical care this can be challenged. Such an approach is increasingly being used and playing a vital role in supporting both those with dementia and relieving the pressures on their family members.

For a long time understanding of dementia has been driven by biomedical perspectives producing in turn, an emphasis on diagnosis, cure and treatment. Of course these are laudable objectives, they do however serve to ‘other’ those with dementia. Through this ‘othering’, those with dementia become subsumed as a clinical entity, people removed from the mainstream identified through their clinical condition or biological problems (Kitwood 1997, p. 44) rather than fellow citizens with associated rights, relationships and people of inherent value. Disability activists such as UPIAS (1976), Barnes (1997) and Oliver (1990) have highlighted how these bio-medical approaches generate systems that ignore the way in which structural barriers and social prejudices actually further disable people especially in relation to policy, comprehensive welfare provision and holistic care. This is more problematic when applied to the potential consequences for the individual who, fearful of the diagnosis and only aware only of its negative stereotypes, becomes understandably reluctant to seek support and advice when confronted with concerns about memory loss and associated symptoms linked to dementia.

For people with dementia their marginalization means they are seen as victims with all the passivity that this implies. Although assessments, care management and interventions are improving in places, the contributions made by Alzheimer's Disease International, Alzheimer Europe and the national Alzheimer Societies demonstrate the need to adopt what Shakespeare (2006) has described as a 'bio-psychosocial' approach. Such a focus emerges as an integral part of effective care systems built on person-centred processes in managing the disease and maintaining dignity and personhood. Juxtaposed is the need to develop improvements in understanding the cognitive and behavioural effects of dementia on the individual by staff and families. This embraces actively promoting their ability to meaningfully communicate with people with dementia. These factors, rather than the containment and despair, have the potential both to embrace individual needs and address the collective marginalization (ADI 2012) of those with dementia.

The prevalence of Dementia

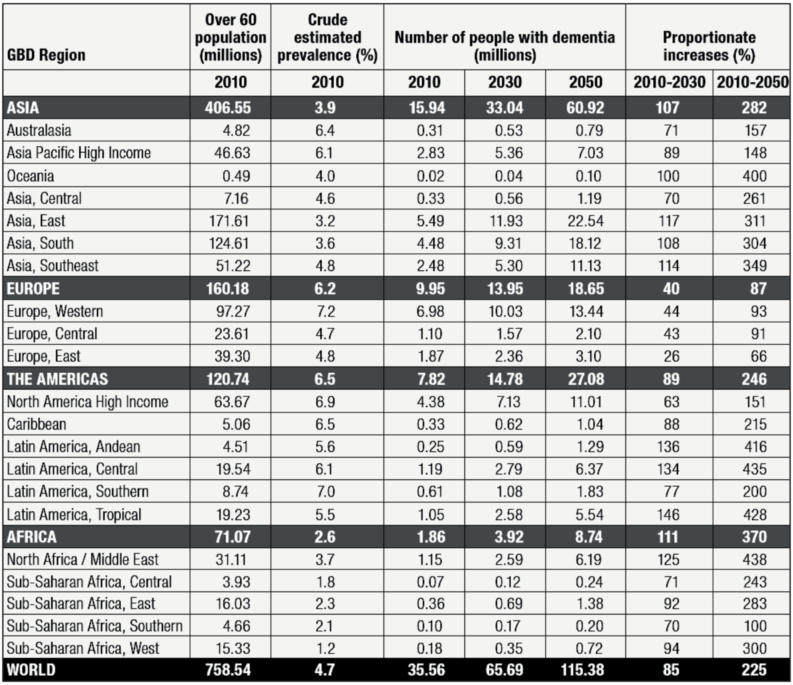
As discussed, a negative effect of advanced ageing is the significant increase in the number of people with Alzheimer's disease and other dementias. Any scientific intention to gain more detailed and comparative knowledge of the epidemiological development of dementia in European countries has to address a range of methodological and diagnostic problems (Riedel-Heller et al 2001). More recently, these challenges have been discussed in the World Alzheimer Report 2009 and by Prince et al (2013). Further, one has to acknowledge that demographic developments are nationally shaped so that any statement on the prevalence and incidence of AD has to be related to the social structure of each European country. It should be noted that many individuals with AD remain undiagnosed, not least because of different priorities, care cultures and health systems (ADI 2013, p. 16). Within the EU member states this emerges in relation to the different ways of addressing care-related issues such as the provision of care, the qualifications and training of professionals and the social perception of dementia (Alzheimer Europe 2012).

Nevertheless, as the World Alzheimer Report 2009 summarises, there are several studies that estimate the implications of ageing populations for the prevalence of dementia in Europe. Based on a systematic review of the global prevalence of dementia identified in 147 studies in what are described as the '21 Global Burden of Disease (GBD) world regions', the 2009 World Alzheimer Report indicates "that the current number of people living with dementia is expected to grow at an alarming rate" (ADI 2009, p. 2). By drawing on a differentiated approach the following characteristics can be identified:

- Looking at the global prevalence of dementia: "58% of all people with dementia worldwide live in low and middle income countries, rising to 71% by 2050. (…) Proportionate increases over the next twenty years in the number of people with dementia will be much steeper in low and middle income countries compared with high income countries." The World Alzheimer Reports 2009 and 2013 forecast "a 40% increase in numbers in Europe, 63% in North America, 77% in the southern Latin American cone and 89% in the developed Asia Pacific countries" (ADI 2009, p. 16; ADI 2013, p. 38).
- Statistics cited by Alzheimer Europe (2008, p. 19) indicated that over 6 million people have dementia in the EU and "it is predicted that this number will double in the next 20 years along with the ageing of the population." The EU funded projects EuroDem (Alzheimer Europe 2009) and EuroCoDe (2006) estimated that the number of people with dementia in 2006 in the EU 27 to rise to between 6.8

and 7.3 million. Subsequent research into the impact of gender on dementia by the European Dementia Research Agenda (ILC 2011) found that of this cohort 2.3 to 2.4 million are men and 4 to 4.9 million are women.

Table 3: Total population over 60, crude estimated prevalence of dementia (2010), estimated number of people with dementia (2010, 2030 and 2050) and proportionate increases (2010-2030 and 2010-2050) by GBD world region (Source: ADI 2010, p.15)



GBD Region	Over 60 population (millions)	Crude estimated prevalence (%)	Number of people with dementia (millions)			Proportionate increases (%)	
	2010	2010	2010	2030	2050	2010-2030	2010-2050
ASIA	**406.55**	**3.9**	**15.94**	**33.04**	**60.92**	**107**	**282**
Australasia	4.82	6.4	0.31	0.53	0.79	71	157
Asia Pacific High Income	46.63	6.1	2.83	5.36	7.03	89	148
Oceania	0.49	4.0	0.02	0.04	0.10	100	400
Asia, Central	7.16	4.6	0.33	0.56	1.19	70	261
Asia, East	171.61	3.2	5.49	11.93	22.54	117	311
Asia, South	124.61	3.6	4.48	9.31	18.12	108	304
Asia, Southeast	51.22	4.8	2.48	5.30	11.13	114	349
EUROPE	**160.18**	**6.2**	**9.95**	**13.95**	**18.65**	**40**	**87**
Europe, Western	97.27	7.2	6.98	10.03	13.44	44	93
Europe, Central	23.61	4.7	1.10	1.57	2.10	43	91
Europe, East	39.30	4.8	1.87	2.36	3.10	26	66
THE AMERICAS	**120.74**	**6.5**	**7.82**	**14.78**	**27.08**	**89**	**246**
North America High Income	63.67	6.9	4.38	7.13	11.01	63	151
Caribbean	5.06	6.5	0.33	0.62	1.04	88	215
Latin America, Andean	4.51	5.6	0.25	0.59	1.29	136	416
Latin America, Central	19.54	6.1	1.19	2.79	6.37	134	435
Latin America, Southern	8.74	7.0	0.61	1.08	1.83	77	200
Latin America, Tropical	19.23	5.5	1.05	2.58	5.54	146	428
AFRICA	**71.07**	**2.6**	**1.86**	**3.92**	**8.74**	**111**	**370**
North Africa / Middle East	31.11	3.7	1.15	2.59	6.19	125	438
Sub-Saharan Africa, Central	3.93	1.8	0.07	0.12	0.24	71	243
Sub-Saharan Africa, East	16.03	2.3	0.36	0.69	1.38	92	283
Sub-Saharan Africa, Southern	4.66	2.1	0.10	0.17	0.20	70	100
Sub-Saharan Africa, West	15.33	1.2	0.18	0.35	0.72	94	300
WORLD	**758.54**	**4.7**	**35.56**	**65.69**	**115.38**	**85**	**225**

- The steady and future growth of ageing populations worldwide is said to lead to a dramatic increase in the number of people with dementia (ADI 2009). This report estimates that there are currently 35.6 million people with dementia with the numbers set to double every 20 years to 65.7 million in 2030 and 115.4 million in 2050.

- The EuroDem studies – using data from 11 population-based studies – show differences in the gender- and age-specific prevalence of dementia/AD. Dementia predominantly affects the over 65s with an estimated ratio of 6.4% and around one in five people over 85 being affected (Lobo et al 2000). After the age of 65, the risk of dementia doubles for every additional five years of life (ILC 2011, p. 11).
- Incidence, which is the rate of new cases occurring in a population in a given time period, is widely considered a more effective measure of disease risk. Following this approach, EuroDem studies shows significant gender differences in the incidences of Alzheimer's disease after 85 years of age, with a higher risk in older women than men. Following Alzheimer Europe (2009), 14% of men and 16% of women aged 80-84 years are estimated to have dementia. For the very old i.e. those aged 90 years and over, these figures rise to 31% of men and 47% of women. However, drawing on other cohort studies which report no difference in incidence rates between men and women, later studies conclude that the gender-dementia association remains open to further research (Carter et al 2012).

Table 4: Prevalence rates of dementia (Europe* and Germany)**

Gender		Age group								
		60-64	65-69	70-74	75-79	80-84	85-89	90-94	95-99	100+
M	EU*	1.4	2.3	3.7	6.3	10.6	17.4	33.4		
	GER**	0.8	1.5	3.2	5.6	10.3	17.9	24.2	29.7	29.7
F	EU*	1.9	3.0	5.0	8.6	14.8	24.7	48.3		
	GER**	0.6	1.3	3.1	6.8	12.8	23.1	31.3	38.0	43.5

* Europe: Meta-analysed estimates of dementia prevalence (Source: ADI 2009, p. 3)
** Germany: Sample from German health insurance (Source: Ziegler/Doblhammer 2009)

- While the calculations of the number of demented people are based on rates from meta-analyses, research by Ziegler and Doblhammer (2009) presents a completely different approach. It calculates the age- and gender-specific prevalence and incidence rates of dementia based on a large sample from the German Sick Funds (GKV) of

2.3 million people from the year 2002. Their study estimates a lower rate of dementia prevalence, significant for both: age groups and gender.

- In contradiction to the scenarios from EuroDem and EuroCoDe, recent surveys from the UK which aim to find out whether the age- and gender-specific dementia rates changed over the decades present more 'optimistic' findings. The author's conclusion that "This study provides compelling evidence of a reduction in the prevalence of dementia in the older population over two decades" (Matthews et al 2013) is linked to a similar Danish cross-sectional cohort study on the physical and cognitive functioning of people older than 90 years (Christensen et al 2013). One of the essential findings from this study is that those born later, not only had significantly better scores for activities of daily living but also a 32% higher chance of reaching 95 years of age. When evaluating both studies it seems "plausible that changes in health behaviour and provision (…) have prevented or delayed the onset of dementia at a population level." Both studies "suggest that lifestyle changes (...) might reduce the risk of dementia and promote more general health and wellbeing" (Banerjee 2013).

The Impact of Dementia

The changes in the population structure as outlined above include a significant increase in the over 65 population. Because chronic diseases tend to be strongly age-associated, there is a need to recognize that the demographic transition causes changes in the profiles and patterns not only of diseases but also in social and economic relationships. The World Alzheimer Report 2009 has analysed this process through three key dimensions:

1. Micro-level: The person with dementia who experiences an 'impaired quality of life and reduced life expectancy'
2. Meso-level: The primary network of the person with dementia, that is family and friends who not only offer care but who themselves are deeply involved often with a marked impact on their own lives

3. Macro-level: The "wider society, which, either directly through government expenditure, or in other ways, incurs the cost of providing health and social care and the opportunity cost of lost productivity" (ADI 2009, p. 48).

The inter-relations between these three dimensions have been explained through the application of various indicators, such as the 'Old-Age Dependency Ratio', the 'Distribution of Dependence' (ADI 2013) or the 'Disability Adjusted Life Years' (DALY). Alzheimer Disease International uses the key indicator DALY, described as "a composite measure of disease burden calculated as the sum of Years Lived with Disability (YLD) and Years of Life Lost (YLL). Thus, the DALY summarises the effects of disease, both on the quantity (premature mortality) and quality of life (disability). These effects are summed across estimated numbers of affected individuals to express the regional and global impact of disease" (ADI 2009, p. 49).

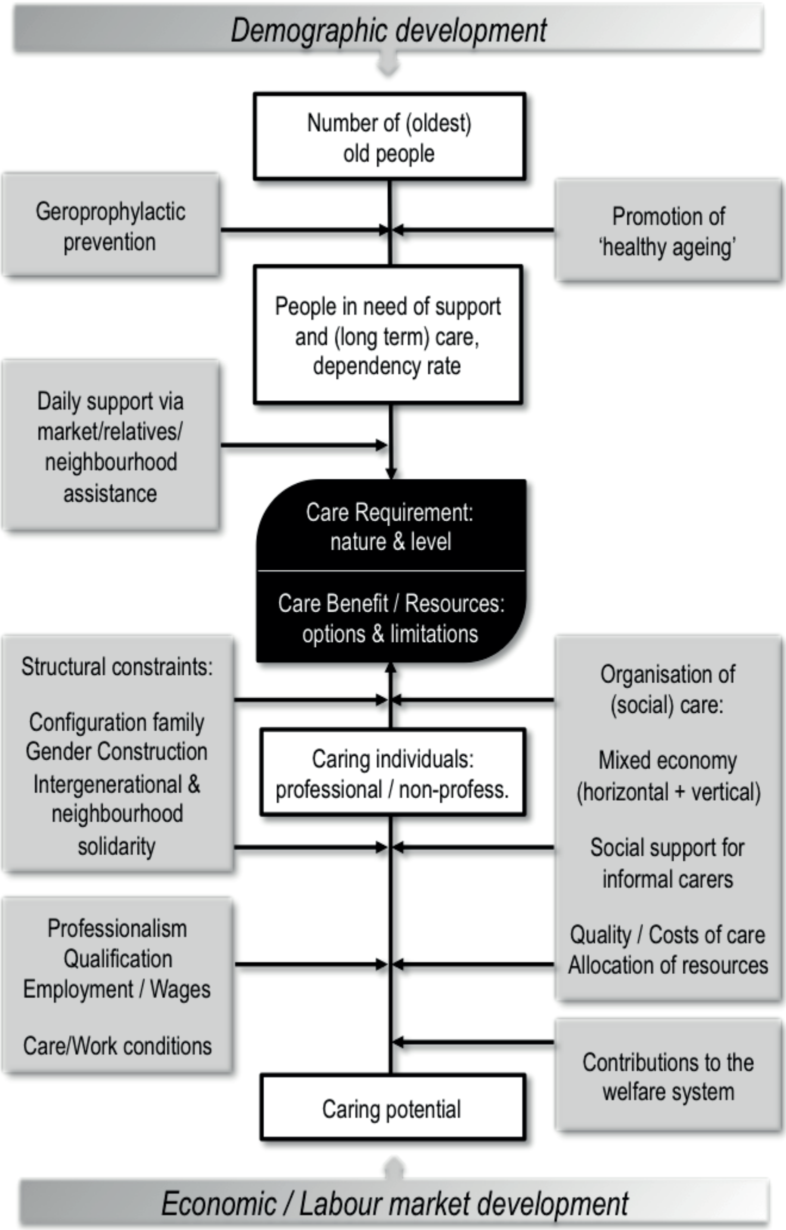
From a wider perspective, the impact of dementia on society and, vice versa, the impact of social change on the living conditions of people with dementia can be analysed by applying a 'balance of care' approach. Within the framework of the dimensions outlined above, this balance can be re-constructed on the micro-level as a balanced sense of self. According to Erikson's theory of personality development (Erikson 1959), the psychosocial crisis represented in the last life stage is that of 'integrity versus despair'. This stage begins when the individual experiences frailty and a sense of mortality. Here according to Erikson ego integrity can be conceptualised as the successful resolution of the final life crisis that is the key to a balanced personality development.

At the meso-level there is a need to focus on balanced economies. With respect to informal care relationships this can be conceptualised as a 'moral economy' (Tronto 1993) that is based on a set of normative attitudes specific to milieus and is driven by moral sentiments such as 'trust', 'duty' or 'love'. 'Balance' in this sense is underpinned by social exchange and reciprocity. With respect to organised care, for a professional system to be classified as 'well balanced', the budget offered and service arrangements provided must be adequate to meet the need for care based on pre-defined standards. It is obvious that these economic relations are linked to political discourses regarding not only the conceptual design of the system of care for elderly people but also its funding arrangements. The latter draws upon 'moral resources' (Dallinger 2009) and values that are communicated within the 'political culture of social welfare' (Döbler 2011). This provides some insight into why questions regarding the sustainability of the 'intergenerational contract' are increasingly being debated at the European level (COM 2005; COM 2007; COM 2009).

At the macro-level the 'balance of care' can be analysed within a complex heuristic model (fig. 4). Within the constraints of demographic and economic developments, the balance between care requirements and care benefits emerges as a complex and permanently on-going process of equilibrium which is influenced by very different factors including:

- The health promoting effects of education, life styles, living conditions (environments) and specific different programmes with an orientation towards 'active ageing'
- The range, availability of and access to 'caring communities' including the varying roles of partners, friends and neighbours; the access to personal and household services' (Angermann and Eichhorst 2013); the value accorded to volunteering and the range of (quasi-) market-driven services
- The (re-)configuration of family structures, including specific life options that are related to gender roles, family histories, family income or housing conditions
- The development of intergenerational solidarity
- The attractiveness and funding for professional care in relation to its place in public funding systems, working conditions, qualification and professionalization
- The organisation of social care services for elderly people within the mixed economy of welfare including service infrastructures that target family caregivers
- The social legitimacy and acceptance of public care expenditure for elderly people
- The political allocation of resources with respect to people with Alzheimer's disease

Fig. 4: Balance of Care

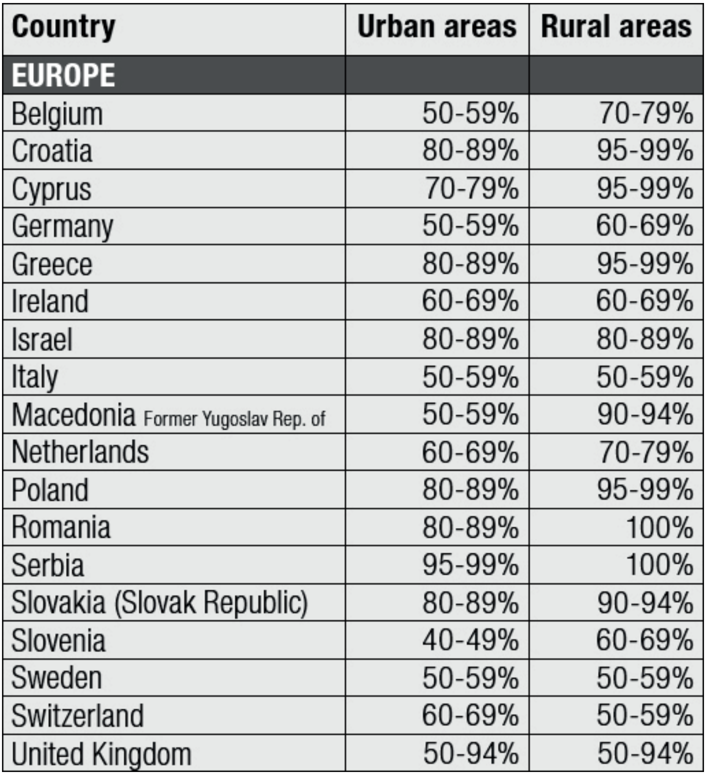


The latest International Expert 'Meeting on Eldercare Services in Europe', organised by the Observatory for Socio-political Developments in Europe (Angermann 2013) highlights that in European terms the provision of eldercare services is very heterogeneous (Angermann and Eichhorst 2012). The factors influencing the 'balance of care' vary according to different national cultures of ageing in relation to the arrangements for family care and welfare configurations. As Mestheneos and Triantafillou state, "The balance of care provision in each country depends on a mixture of factors such as tradition, legal responsibilities, health and social policy, national budgets and national wealth and, last but not least, demographic trends regarding fertility levels and life expectancy, which affect the availability of informal family carers" (Mestheneos and Triantafillou, 2005, p.14)

By compiling comparative data on the situation of family carers contained in 23 different (trans-)national reports and surveys, the EUROFAMCARE study (Lamura et al. 2008) states that the nature of family care for older people is complex. This led Mestheneos and Triantafillou, 2005 to conclude that "Shared histories, love and mutual obligations are at the heart of an interpersonal social solidarity" that enables emotional and practical exchange between family members (Mestheneos and Triantafillou, 2005, p.17). As a consequence of these factors there are 'substantive differences' between countries in Europe regarding how care is provided. These differences are significant with respect to both formal and informal care provision. However, despite variations in national systems some commonality can be identified including:

- Research data on the proportion of people with dementia that are living at home is controversial. Data from the Dementia Carers' Survey (Alzheimer Europe 2008), carried out by Alzheimer Europe and its members organisations in France, Germany, Poland, Scotland and Spain, estimate that 84% of patients were cared for at home. Data from the ADI survey show a very unclear and – in European comparison – rather heterogeneous picture (Table 5). The proportion of people with dementia residing at home is higher in low-income countries and in rural areas. As articulated in the World Alzheimer Report, "In high income countries, the mean proportion living at home is 66% (…), while in low and middle income countries 94% of people with dementia live at home” (ADI 2010, p. 18).

Table 5: Estimated proportion of people with Dementia that are living at home (%) (Source: ADI 2010, p.18 – extract from the original)



Country	Urban areas	Rural areas
EUROPE		
Belgium	50-59%	70-79%
Croatia	80-89%	95-99%
Cyprus	70-79%	95-99%
Germany	50-59%	60-69%
Greece	80-89%	95-99%
Ireland	60-69%	60-69%
Israel	80-89%	80-89%
Italy	50-59%	50-59%
Macedonia Former Yugoslav Rep. of	50-59%	90-94%
Netherlands	60-69%	70-79%
Poland	80-89%	95-99%
Romania	80-89%	100%
Serbia	95-99%	100%
Slovakia (Slovak Republic)	80-89%	90-94%
Slovenia	40-49%	60-69%
Sweden	50-59%	50-59%
Switzerland	60-69%	50-59%
United Kingdom	50-94%	50-94%

- In all European countries family members as informal carers provide the majority of care. Alzheimer Europe (2008) found that half of carers of people with severe-stage dementia spent more than 10 hours each day caring. Family carers, approximately two thirds of which were unpaid women, provided their labour in order to support their dependent older person at home.

- Attitudes towards family care vary throughout Europe and are influenced by different social constraints and life trajectories within and across the individual countries.
- Care on the basis on interpersonal social solidarity is said to become difficult as a result of
    - Increases in divorce rates and remarriage. This is linked to the demise of the traditional ligatures and family loyalties regarding familial obligations and willingness to care. Generally speaking, changing family structures due to divorce, family breakdown and economic migration reduce the availability of informal carers;
    - The older person's needs becoming such that they require help over and beyond 'normal interchanges' (Mestheneos and Triantafillou, 2005, p. 17). This is most marked when there are 'challenging behaviours' and difficulties in performing the ADL's. According to Alzheimer Europe (2008), it is these aspects that are perceived to be most problematic for family carers to cope with.
- Carers show significant psychological and physical illness with high levels of anxiety and depression. A survey by the UK Alzheimer's Society indicated "That nearly 60% of carers reported suffering ill health or nervous problems as a result of direct caring. Further research has shown that up to half of caregivers become depressed" (Dunkin and Anderson-Hanley 1998, cit. in: Alzheimer Europe 2008, p. 4)
- Some countries report "A trend in the decline in willingness to provide hands on care especially amongst the better educated and those with better jobs" (Mestheneos and Triantafillou, 2005, p. 26). This trend is also notable, when the labour market participation rate by women increases and the availability of long-term care insurance allows a retreat from family-based care.
- The share and importance of formal or informal care arrangements show major disparities, which can be explained "by the stronger or weaker institutional support of these sectors in the various European countries" (Angermann and Eichhorst 2012, p. 6).
- Although the data available on employment in the care sector is hardly comparable, it can be noted that the majority of professional

eldercare workers, both in personal care and household services, are women, usually from relatively poorer backgrounds with lower educational attainment. In many EU Member States they operate within low-income jobs, in ever-worsening working conditions and through atypical patterns of employment.

- Due to recruitment and retention problems, most European countries are experiencing a shortage of formal long-term care staff. „These shortages have placed enormous burdens not only on care providers, but also on already vulnerable service users. Older people using services, especially those receiving home and residential care, often endure rushed care, loss of continuity, higher risk of injuries, and loss of experienced carers“ (Hussein and Manthorpe 2005, p. 7).
- In countries where institutionalised long-term care is widely available, "the onset of cognitive decline is often the precipitant for institutional placement" (ADI 2009, p. 51). Approximately three quarters or more of nursing home residents have dementia.
- According to Angermann and Eichhorst (2012), "The shift of eldercare services from the informal to the formal sector, the availability of formal services, their quantity and quality, but also the working conditions of eldercare staff are strongly influenced by to what extent an adequate and sustainable funding is provided" (Angermann and Eichhorst 2012, p.25). In international comparison the level and structure of expenditure (also: cash or care) varies depending on the allocation of financial resources within the frame of specific welfare and/or caring traditions.
- Most European countries favour policies that try to reduce institutional care by developing home-based and community services. Discussions on this balance, however, should include arguments that address the frictions and limitations of family or community based care and vice versa the 'quality of life options' (Diaz-Ponce and Cahill 2013) that are offered within quality care environments run as highly specialised dementia units. Further, it would be inaccurate to assume "that a shifting balance between institutional and community care will necessarily save money" (Knapp et al. 2007, p.14).

The provision as well as the utilization of services is determined by a range of political, economic and individual priorities which dictate supply and demand (Wimo et al. 2009). Moreover, demand for support and services does not exist in a vacuum, rather it is influenced by other factors such as gender, culture, income and socio-economic status, social class and education (Mooney 2003). Alzheimer Europe highlight how across Europe "Carers face significant gaps in the information, help and support they receive and only 17% considered that the level of care for the elderly in their country was good" (Alzheimer Europe 2008, p. 5). This study found that between 68,5% (Germany) and 84,6% (France) of the people questioned shared the opinion that the government's spending on caring for people with dementia should be increased.

More detailed information about the European dementia 'care cultures' can be found in the Eurobarometer 2007 that focuses on attitudes to the care of elderly and dependent people. The report summarises that „European public broadly supports the idea that public authorities should provide appropriate home care and institutional care for elderly people in need (…) There is also widespread agreement with the notion that family carers should receive (financial) support from the state (…). There is clear opposition to the notion that close relatives should provide the care (58% disagree)" (COM 2007b, p. 68).

To sum up, a comparison of eldercare services within Europe shows a huge variety in both how the services are delivered and how these services are embedded into welfare structures and cultures. Across Europe the funding of long-term care for older people is organised within four main systems: out-of-pocket payments, private insurance, tax-based support and social insurance. These main financing approaches differ in various ways, including the balance between private and public funding, the nature, extent and limit of risk pooling and their future affordability. What can be seen is that the gap between older people in need and caring relatives increases. Formal professional services for elderly people will require more resources over the coming decades.

The Costs of Dementia

Although spending on dementia services across European states is never an insignificant amount of GDP, dementia is acknowledged to be an expensive condition (Alzheimer's Society UK 2013) which places considerable demands on both public and private finances. In fact, the financial costs of dementia in Europe are difficult to quantify. The care, medical and related needs of people with dementia undoubtedly make substantial demands on national, local and family resources (Johnson et. al, 2000; Wahlbeck et al.1996), which increase with disease severity and progression. Methodological differences between studies make financial comparisons alone across and between countries, social and healthcare systems very challenging (Wahlbeck and McDaid 2012). Moreover, given the 'welfare-mix' of the various welfare typologies found across Europe, then in order to make a meaningful comparative analysis, there is clearly a need to standardize these arrangements and parameters.

With respect to methodological issues when estimating the cost of caring for person with dementia, the World Alzheimer Report 2010 discusses the economic impacts by making use of 147 studies in 21 Global Burden of Disease world regions and aggregating data up to the level of World Bank income groupings. It comes to the conclusion that "Alzheimer's and other dementias are imposing huge societal economic burdens, both through direct (medical and social care) and indirect (unpaid caregiving by families and friends) costs" (ADI 2010, p. 8). Dementia significantly affects all health and social care systems, but its economic impact has to be calculated according to a complex set of variables including the countries' specific prevalence/incidence of dementia; the countries' income levels and the growing impact of different mixed economies of care systems. In fact, in order to estimate costs accurately and to apportion costs appropriately within sectors, it is crucial to estimate the relative proportions of people with dementia living at home, those in long-term residential or nursing home care facility or living in specialist facilities for people with Alzheimer's disease – each of these can provide care and support that ranges from low to high intensity. These arrangements can be delivered using staff with wide-ranging levels of professional education or training and a variety of qualifications.

In most countries, there is no published data on this aspect of dementia care expenditure.

Aiming for a deeper analysis, the World Alzheimer Report 2010 refers to a research approach that sub-classifies the cost of dementia as direct medical costs, direct social care costs and indirect costs. Direct cost calculations are typically based on the value of resources used, while indirect costs are based on resources lost. Direct medical costs refer to sickness benefits in kind (for example, medication and visits to clinics), direct social care costs arise from formal services provided outside the medical care system (for example personal and household services, residential or nursing home care). This approach highlights the complexity and associated challenges of quantifying the cost of dementia.

In contradiction to a cost calculation that is based on a formal budget, costing informal – mostly unpaid or low paid – care is both complicated and controversial. When following the ‘replacement cost approach’ it has to be estimated how much time family caregivers spend caring, including time spent linked to the basic activities of daily living (ADL), on the instrumental activities of daily living (IADL) and in relation to the supervision of the person and related management of the behavioural symptoms of dementia or in preventing dangers arising. As such it has been asserted that “the replacement cost approach assumes that the informal caregiver’s inputs should be calculated according to the cost of replacing them with a professional caregiver” (ADI 2010, p. 17).

Detailed projection models from Germany, Italy, Spain and UK indicate that re-arranging care scenarios with a shift towards professional home-based care and/or institutional care would cause significant effects on the expenditure expressed as a percentage of GDP. Giving testimony to the economic role of informal carers, it has been predicted that “a decline in informal care of 0.5%, accompanied by a rise in institutional care, would raise the proportion of GDP spent on long-term care expenditure (…) by between 10% and nearly 60% in 2050“ (Pickard 2003a, p. 201). The scenario is even more dramatic if all “those with moderate to severe dependency were given an entitlement to an average package of home care” (Pickard 2003b, p. 225).

In order to calculate what has been described as the ‘opportunity costs’ it is necessary to identify the possible alternative uses of the caregiver’s time. This approach defines the cost of dementia as the amount of lost income for those carers who have given up paid employment or cut back their working hours to meet their caring roles and responsibilities. Lost employment revenues also means a loss of taxes paid to respective governments.

It is obvious that it is “almost impossible to identify health or social care expenditure that is exclusively targeted on people with dementia” (Knapp et al. 2007, p.9). Not only the quantification of informal care but also the costing of both, replacing professional caregivers and loosing opportunities, is crucial for the final estimated total costs. Adopting a model premised on income levels, the World Alzheimer Report 2010 highlights the following trends:

- About 70% of the costs occur in Western Europe and North America.
- The cost of informal care and the direct costs of social care contribute similar proportions of the total costs, while the direct medical costs are much lower. This could be an indication of “low levels of awareness and help-seeking“, a matter of “distinction between health and social care” (Knapp et al. 2007, p. 12) or simply “because there are currently no pharmacological treatments that have proven to be effective in preventing or modifying the course of the disease“ (ADI 2010, p. 45).
- In high-income countries, the direct costs of dementia care exceeds informal care costs, with the cost of institutional care in residential and nursing care facilities dominating (ADI 2009, p.9).
- In the low income and lower middle-income countries informal care constitutes the majority of costs.
- The direct costs for social care have a much larger role in the high-income countries. “The total cost per person with dementia is 38 times higher in high income countries than in low income countries, and the direct costs of social care are 120 times higher” (ADI 2010, p. 24).

- All of the countries have, as summarised in the Report for the National Audit Office, UK, increased the resources they devote to long-term care over recent years. “But they are all also wrestling with the challenge of how to find considerably more resources in the future” (Knapp et al. 2007, p. 8f.). The demand for formal care services by the population is likely to grow substantially. The provision of long-term care services for frail and elderly people and the ratio of long-term care expenditure to GDP is expected to rise within the next decades (ADI 2013a; Angermann and Eichhorst 2012).

European initiatives on Alzheimer’s disease and other dementias

Until now, there are no health care treatments for stopping or curing dementia. As such social care plays an important role in supporting those with Alzheimer’s disease. Social care is provided in different ways: informally by family members or friends, within intermediate structures by volunteers or formally by a range of different professionals. These actors participate in the ‘balance of care’, which – as already outlined – has to be understood in terms of national welfare systems producing significant variations and approaches to treating dementia as a social problem. At the transnational level the age-related topics of ‘An age-friendly EU’ (AGE 2012), ‘Meeting social needs in an ageing society’ (COM 2008) and finally ‘The fight against Alzheimer‘s disease and related disorders’ (EU Presidencies 2008), as the latest G8 summit held in London on Dec. 11th, 2013 claimed, are now at the top of the political agenda. This actual and symbolic event can be traced back to the written declaration of the European Parliament (2008) which called on the Commission, the Council and the governments of the Member States to recognise Alzheimer’s disease as a European public health priority and to develop a European action plan.

The claim for priority action given, the context of an ageing EU‘s population was adopted by the European Commission on the 22nd of July 2009 and communicated to the European Parliament and the Council of the European Union: “The specific characteristics of Alzheimer‘s disease and other dementias single them out as a domain of potential European added value. The objective of this Communication is to set out actions providing support to Member States in ensuring effective and efficient recognition, prevention, diagnosis, treatment, care, and research for Alzheimer‘s disease and other dementias in Europe“ (COM 2009b, p. 3). The Communication from the Commission to the European Parliament and the Council on a European initiative on Alzheimer‘s Disease and other dementias draws on the findings of EuroCoDe (European Collaboration on Dementia). On 19th January 2011, the European Parliament called for dementia to be made a EU health priority and urged Member States to develop dedicated national strategies. This European initiative (European Parliament, 2011) is outlined as 65 strategic topics, which date back to the ‘Paris Declaration’ that was signed by the members of ‘Alzheimer Europe’ in 2006 (Alzheimer Europe 2006). It is also linked to most of the recommendations which ‘Alzheimer’s Disease International’ reminded EU and national governments of in the World Alzheimer Report 2010 (ADI 2010). The political priorities as outlined in these central European documents can be clustered into the following key areas:

- National strategies for Alzheimer‘s disease in order to deal with the social and health consequences of dementia and to provide services and support for people with dementia and their families
- Coordinated research in the field of neuro-degenerative diseases (epidemiological and clinical studies) and exchange of good practices for treatment and care across Europe
- Prevention-orientated health promotion based on ‘a healthy lifestyle for a healthy brain’
- Improvements linked to early diagnosis, corresponding treatments and appropriate support
- Multidisciplinary services delivery in communities and at home, regardless of age, gender, ethnicity, wealth, disability and rural or urban residence
- Common guidelines and safety standards that are applicable to caring institutions, to communities and to home care arrangements
- New skill-specific jobs to look after an increasingly dependent ageing population.

- Acknowledging the specific needs of women in the areas of health, employment and social policies
- Promoting the role of Alzheimer's associations and providing them with regular formalised support
- Developing patients‘ associations and support groups for healthcare professionals and for relatives
- Addressing wider ethical questions including the rights, autonomy and dignity of people with dementia.

Conclusion

Dementia, including Alzheimer's disease, is now recognised as one of the biggest global public health challenges. The latest prevalence figures, published by Alzheimer's Disease International, predict a shift in the distribution of the global burden of dementia: "The new estimates are an increase of 17% on the figures published in 2009, with data showing that the number of people with dementia will increase from 115 to 135 million by 2050". The report also highlights that "In the next few decades, the global burden of dementia will shift inexorably to poorer countries, particularly rapidly developing middle income countries“ where access to social protection, care services and support are very limited (ADI 2013, p. 5).

Nevertheless, policy briefings across the EU member states should take into account that dementia is definitely part of the challenge of Europe's ageing population. It is evident that the need for the public provision of services will increase. The fiscal impact of ageing is projected to be substantial in almost all member states. Although informal care is the most important source of support for dependent older people in all European countries, future trends suggest that informal care is likely to decline in all the countries in the long-term.

Due to the ageing of the population a further increase in the demand for health workforce is expected. "Policy makers need to consider two parallel and inter-associated strategies; one to improve direct care workers' job conditions and the other to explore and evaluate the creation of new pools of supply for the growing demand for the social care workforce“ (Hussein and Manthorpe 2005, p. 12). In contradiction to this clear strategic recommendation there are generalized reports of reductions in nursing and care posts across Europe. Pay cuts and salary freezes for those employed in this area, diminished recruitment and retention rates and observed compromises in quality of care and patient safety (EFN, 2012) will not be without consequences for those with dementia or their carers.

Generally should be noted that monetary systems for formal care are highly sensitive to economic factors. With financial resources in the health, care and social security systems under increasing stress and the predicted growth in the number of people with dementia, the question on how to improve care and fund future care will be critical. In particular, as the examples from those countries which are most significantly affected by the economic crisis demonstrates, where meeting need is determined by an ability to pay, then this will influence provision, access and the associated take-up of services (Alzheimer Europe 2012). The effects of the global financial crisis on people with dementia may be obvious, but to date there appear to have been few systematic attempts to actually measure these.

In several European countries politicians and employers have also attempted to erode national terms and conditions. As a result of these factors and the rising demand for dementia services, many care systems in Europe are under tremendous pressure to deliver efficiency savings, introduce austerity measures in an economically constrained climate. This is occurring while nation states are also responding to increasing expectations around service quality, the rising costs of drugs and also generating new approaches and changes to the commissioning and provision of dementia services as an outcome of shifts towards marketization and the commodification of welfare.

The warning of the global impact of dementia comes at a difficult time for most European health and social care systems with public and private budgets under huge strain. This has produced marked slowdown and actual reductions in health and social care spending in several EU countries as part of their broader efforts to reduce budgetary deficits and associated ideological shifts towards marketization. It is probably too early to predict the outcomes of these objectives (changing health and social care profiles take years rather than months to manifest), however, the emerging OCED, WHO Europe and Eurostat indicators are not good (OCED 2012). It is unlikely that dementia services will be spared from this economic culling of public services.

References

AGE (2012) Towards an Age-Friendly European Union by 2020, Brussels: AGE Platform Europe. Available from: http://www.age-platform.eu/images/stories/EN/towards_an_age_friendly_eu_final.pdf (10.12.2013)

Agüero-Torres, H., von Strauss, E., Viitanen, M., Winblad, B. and Fratiglioni, L. (2001). Institutionalization in the elderly: the role of chronic diseases and dementia. Cross-sectional and longitudinal data from a population-based study. Journal of Clinical Epidemiology 54, pp. 795-801.

ADI - Alzheimer's Disease International (2013) World Alzheimer Report 2013: Journey of Caring. An analysis of long-term care for dementia, London: ADI

ADI - Alzheimer's Disease International (2013) Policy Brief for Heads of Government. The Global Impact of Dementia 2013 -2050, London: ADI. Available from: http://www.alz.co.uk/research/GlobalImpactDementia2013.pdf (05.12.2013)

ADI - Alzheimer's Disease International (2012) World Alzheimer Report 2012. Overcoming the stigma of dementia, London: ADI. Available from: http://www.alz.co.uk/research/WorldAlzheimerReport2012.pdf (05.12.2013)

ADI - Alzheimer's Disease International (2010) World Alzheimer Report 2010: The Global Economic Impact of Dementia, London: ADI

ADI - Alzheimer's Disease International (2009) World Alzheimer Report 2009, London: ADI

ADI - Alzheimer's Disease International (2008) The prevalence of dementia worldwide, December 2008, London. Available from: http://www.alz.co.uk/adi/pdf/prevalence.pdf (31.10.2013)

Alzheimer Europe (2012) Dementia in Europe Yearbook 2012. National Dementia Strategies. Luxembourg: Alzheimer Europe.

Alzheimer Europe (2009) Prevalence of dementia. European Collaboration on Dementia (EuroDem). Available from: http://www.alzheimer-europe.org/Research/European-Collaboration-on-Dementia/Prevalence-of-dementia (01.11.2013)

Alzheimer Europe (2008) Dementia in Europe Yearbook 2008 - with a focus on social support, socio-economic cost, psychosocial interventions and prevention. Luxembourg: Alzheimer Europe.

Alzheimer Europe (2006a) Political Priorities: Paris Declaration. Available from: http://www.alzheimer-europe.org/EN/Policy-in-Practice2/Paris-Declaration/Executive-Summary (12.12.2013)

Alzheimer Europe (2006): Who cares? The state of dementia care in Europe; Dementia Carers‘ Survey. Available from: http://www.alzheimer-europe.org/FR/Alzheimer-Europe/Our-work/Completed-AE-projects/2006-Dementia-Carers-Survey (27.10.2013)

Alzheimer Scotland (2007) A positive Choice – choosing long-stay care for a person with dementia. Available from: http://www.alzscot.org/assets/0000/0267/positivechoice.pdf (31.10.2013)

Alzheimer’s Society UK (2013). Financial Cost’s of Dementia. London: Alzheimer’s UK.

Alzheimer’s Society UK (2013a) Depression and anxiety. Available from: http://www.alzheimers.org.uk/site/scripts/download.php?fileID=1768 (31.10.2013)

Andersen, K., Launer, L.J., Dewey, M.E., Letenneur, L., Ott, A., Copeland, J.R., Dartigues, J.F., Kragh-Sorensen, P., Baldereschi, M., Brayne, C., Lobo, A., Martinez-Lage, J.M., Stijnen, T., and Hofman A. (1999) Gender differences in the incidence of AD and vascular dementia: The EURODEM Studies. EURODEM Incidence Research Group. Neurology 10, 53 (9), pp. 1992-1997.

Angermann, A. (2013) Eldercare Services in Europe – Personal and Household Services for Older People. International Expert Meeting 16.09.2013, Berlin: Observatory for Socio-political Developments in Europe. Available from: www.beobachtungsstelle-gesellschaftspolitik.de/uploads/tx_aebgppublications/Expert_Meeting_PHS_Sept2013_OBS.pdf (30.11.2013)

Angermann, A. and Eichhorst, W. (2013) Who Cares for You at Home? Personal and Household Services in Europe (IZA Policy Paper No. 71), Bonn: Institute for the Study of Labour. Available from: http://ftp.iza.org/pp71.pdf (30.11.2013)

Angermann, A. and Eichhorst, W. (2012) Eldercare Services – Lessons from a European Comparison (Working Paper No. 6 of the Observatory for Socio-political Developments in Europe /IZA Research Report No. 45), Berlin: German Association for Public and Private Welfare. Available from: http://www.sociopolitical-observatory.eu/uploads/tx_aebgppublications/Working_Paper_6_OBS_IZA.pdf (30.11.2013)

Banerjee, S. (2013) Good news on dementia prevalence – we can make a difference, The Lancet, Vol. 382, Issue 9902, pp. 1384-1386.

Baltes, M. M. (1998). The psychology of the oldest-old: The Fourth Age. Current Opinion in Psychiatry, 11, pp. 411-415.

Baltes, P.B and Baltes, M.M. (1993) Successful Aging. Perspectives from the Behavioral Sciences, Cambridge University Press

Barnes, C. (1997) A Legacy of Oppression: a History of Disability in Western Culture. In Barton, L. and Oliver, M. (eds.), Disability Studies: Past Present and Future. Leeds: The Disability Press.

Beck, U. and Beck-Gernsheim, E. (2002) A life of one‘s own in a runaway world: Individualization, globalization and politics. In Theory, Culture & Society: Individualization: Institutionalized individualism and its social and political consequences. (pp. 22-30). London: SAGE Publications Ltd., pp. 22-30.

Berlin-Institut für Bevölkerung und Entwicklung (2011) Demenz-Report. Wie sich die Regionen in Deutschland, Österreich und der Schweiz auf die Alterung der Gesellschaft vorbereiten können, Berlin/Köln. Available from: http://www.berlin-institut.org/fileadmin/user_upload/Demenz/Demenz_online.pdf (12.12.2013)

Blendon, R.J., Benson, J.M., Wikler, E.M., Weldon, K.J., Georges, J., Baumgart, M. and Kallmyer, B.A. (2012) The Impact of Experience with a Family Member with Alzheimer’s Disease on Views about the Disease across Five Countries, in: International Journal of Alzheimer’s Disease, Vol. 2012, pp. 1-9.

Carter, C. L., Resnick, E. M., Mallampalli, M. and Anna Kalbarczyk, A. (2012) Sex and Gender Differences in Alzheimer’s Disease: Recommendations for Future Research, Journal of Women’s Health 21, 10, pp. 1-6.

Christensen, K., et al., Physical and cognitive functioning of people older than 90 years: a comparison of two Danish cohorts born 10 years apart, The Lancet, Early Online Publication, 11 July 2013 doi:10.1016/S0140-6736(13)60777-1. Available from: http://www.thelancet.com/journals/lancet/article/PIIS0140-6736%2813%2960777-1/abstract (05.10.13)

Chung, J. A. and Cummings, J. L. (2000). Neurobehavioral and neuropsychiatric symptoms in Alzheimer‘s disease: characteristics and treatment. Neurol Clin, 18 (4), pp. 829-846.

Cohen-Mansfield, J. (1996) Behavioral and mood evaluations: assessment of agitation. International Psychogeriatrics 8, pp. 233-245.

Corrada, M. et al (2010) Dementia – Incidence continues to increase with age in the oldest-old: The 90+ study, in: Annals of Neurology 60, 1, pp. 114-121.

EuroCoDe: Report of WP 7 2006. Prevalence of Dementia in Europe (Working paper). Available from: http://ec.europa.eu/health/archive/ph_information/dissemination/diseases/docs/eurocode.pdf. (01.11.2013)

European Federation of Nursing Association (2012) The Impact of the Financial Crisis on Nurses and Nursing: EFN.

COM (2011) European Commission. The 2012 Ageing Report: Underlying Assumptions and Projection Methodologies, European Economy 4/2011, Brussels. Available from: http://ec.europa.eu/economy_finance/publications/european_economy/2011/pdf/ee-2011-4_en.pdf (01.11.2013)

COM (2009) European Commission, Flash Eurobarometer: Intergenerational solidarity – Analytical report, April 2009. Available from: http://ec.europa.eu/public_opinion/flash/fl_269_en.pdf (05.12.2013)

COM (2009a) Memorandum to the Commission. Communication from the Commission to the Council and the European Parliament on a European initiative on Alzheimer’s disease and other dementias. Available from: http://ec.europa.eu/health/ph_information/dissemination/documents/com2009_380_memo_en.pdf (12.12.2013)

COM (2009b) 380 final – Commission of the European Communities, Brussels, 22.07.2009: Communication from the Commission to the European Parliament and the Council on a European Initiative on Alzheimer’s Disease and other Dementias. Available from: http://ec.europa.eu/health/ph_information/dissemination/documents/com2009_380_en.pdf (12.12.2013)

COM (2008) SEC (2008) 2911 – Commission of the European Communities, Brussels: Demography Report 2008: Meeting Social Needs in an Ageing

Society. Available from: http://ec.europa.eu/social/BlobServlet?docId=709&langId=en (10.12.2013)

COM (2007a) 244 final – Commission of the European Communities, Brussels, 10.5.2007: Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions: Promoting Solidarity between the Generations. Available from: http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2007:0244:FIN:EN:PDF (05.12.2013)

COM (2007b) European Commission, Special Eurobarometer: Health and long-term care in the European Union, Report, Dec. 2007. Available from: http://ec.europa.eu/public_opinion/archives/ebs/ebs_283_en.pdf (05.12.2013)

COM (2005) 94 final – Commission of the European Communities, Brussels, 16.3.2005: Green Paper "Confronting demographic change: a new solidarity between the generations". Available from: http://eur-lex.europa.eu/LexUriServ/site/en/com/2005/com2005_0094en01.pdf (05.12.2013)

COM Public Health: European Commission: Public Health, Alzheimer disease and other dementias. Available from: http://ec.europa.eu/health/major_chronic_diseases/diseases/alzheimer/index_en.htm (12.12.2013)

Comas-Herrera, A. and Wittenberg, R. (2003) European Study of Long-Term Care Expenditure: Investigating the sensitivity of projections of future long-term care expenditure in Germany, Spain, Italy and the United Kingdom to changes in assumptions about demography, dependency, informal care, formal care and unit costs. (Report to the European Commission, Employment and Social Affairs DG), London: The London School of Economics

Dallinger, U. (2009) Die Solidarität der modernen Gesellschaft. Der Diskurs um rationale oder normative Ordnung in Sozialtheorie und Soziologie des Wohlfahrtsstaates, Wiesbaden: VS Verlag für Sozialwissenschaften.

Diaz-Ponce, A. and Cahill, S. (2013) Dementia and Quality-of-Life Issues in Older People, in: Phellas, C (ed.) Aging in European Societies. International Perspectives on Aging Vol. 6, N.Y.; Heidelberg; Dordrecht; London: Springer, pp. 97-115.

Döbler, J. (2011) The German Welfare System – Traditions & Transitions, in: Gjallerhorn. Tidsskrift for professionsuddannelser 13, pp. 16-30.

Dunkin, J.J. and Anderson-Hanley, C. (1998) Dementia caregiver burden: A review of the literature and guidelines for assessment and intervention. Neurology 1998; 51, s53-s60

EFN – European Federation of Nursing Association (2012) The Impact of the Financial Crisis on Nurses and Nursing: EFN

Erikson, E.H. (1959) Identity and the Life Cycle, New York: International Universities Press

EU Presidencies (2008) The fight against Alzheimer's disease and related disorders, conference, 30th and 31st October 2008, Paris: Bibliothèque nationale de France. Available from: http://medias.demo.doctissimo.fr/medias-factory-alzheimer/static/pdf/Alzheimer_conference_EN_081030.pdf (10.12.2013)

European Parliament (2011) European Parliament resolution of 19 January 2011 on a European initiative on Alzheimer‘s disease and other dementias. Available from: http://www.europarl.europa.eu/sides/getDoc.do?-type=TA&language=EN&reference=P7-TA-2011-0016 (12.12.2013)

European Parliament (2008) Written Declaration on Priorities in the Fight against Alzheimer's Disease. Available from: http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//NONSGML+W-DECL+P6-DCL-2008-0080+0+DOC+PDF+V0//EN&language=EN (12.12.2013)

Eurostat EU COM (2011) Statistical books. Active ageing and solidarity between generations. A statistical portrait of the European Union 2012, Luxembourg. Available from: http://epp.eurostat.ec.europa.eu/cache/ITY_OFFPUB/KS-EP-11-001/EN/KS-EP-11-001-EN.PDF (01.11.2013)

Eurostat EU COM (2010) Demography Report 2010: Older, more numerous and diverse Europeans, Mscr. completed in March 2011. Available from: http://ec.europa.eu/social/BlobServlet?docId=6824&langId=en (27.10.2013)

Eurostat EU COM (2008), Europe in Figures, Eurostat Yearbook 2008. Available from: http://epp.eurostat.ec.europa.eu/cache/ITY_OFFPUB/KS-CD-07-001/EN/KS-CD-07-001-EN.PDF (27.10.2013)

Ferri, C.P. Prince, M., Brayne, C., Brodaty, H. et al (2005) Global prevalence of dementia – a Delphi consensus study. Lancet 366 (9503), pp. 2112-2117.

Galasko, D., Bennett D., Sano M. et al. An inventory to assess activities of daily living for clinical trials in Alzheimer's disease: the Alzheimer's Disease Cooperative Study. Alzheimer Dis Assoc Disord. 1997; 11 (suppl 2), s33-s39.

Giannakouris, K. (2008) Ageing characterises the demographic perspectives of the European societies, Eurostat, Statistics in focus 72/2008. Available from: http://epp.eurostat.ec.europa.eu/cache/ITY_OFFPUB/KS-SF-08-072/EN/KS-SF-08-072-EN.PDF (31.10.2013)

Gräßel, E. (2002). When home care ends – changes in the physical health of informal caregivers caring for a dementia patient: a longitudinal study. J Am Geriatric Soc 2002; 50, pp. 843-849.

Gräßel, E. (1998). Häusliche Pflege dementiell und nicht dementiell Erkrankter. Teil II: Gesundheit und Belastung der Pflegenden. Z Gerontol Geriatr 1998; 31, pp. 57-62.

Halek, M. and Bartholomeyczik, S. (2006) Verstehen und Handeln. Forschungsergebnisse zur Pflege von Menschen mit Demenz und herausforderndem Verhalten, Witten, Universität Witten/Herdecke.

Haski-Leventhal, D. (2009) Elderly Volunteering and Well-Being: A Cross-European Comparison Based on SHARE Data, in: VOLUNTAS: International Journal of Voluntary and Nonprofit Organizations, Vol. 20, 4, pp. 388-404.

Harvard School of Public Health and Alzheimer Europe (2011) Five-Country Alzheimer‘s Disease Survey. Available from: http://www.hsph.harvard.edu/news/files/2012/11/alzheimers_topline.doc (05.12.2013)

Havighurst , R.J. (1961) Successful aging. Gerontologist. 1961, 1, pp. 8-13.

Hofman, A., Rocca, W.A., Brayne, C., Breteler, M.M. et al. (1991) The prevalence of dementia in Europe: a collaborative study of 1980-1990 findings. International Journal of Epidemiology, 20, 3, pp. 736-748.

Hussein, S. and Manthorpe, J. (2005) An International Review of Long Term Care

Workforce: Policies and Shortages, in: Journal of Aging and Social Policy, 17 (4), p. 75-94. Available from: http://www.academia.edu/2289042/An_International_Review_of_Long_Term_Care_Workforce_Policies_and_Shortages (21.12.2013)

ILC (2011) The International Longevity Centre, The European Dementia Research Agenda, February 2011. Available from: http://ilcuk.org.uk/files/pdf_pdf_165.pdf (27.10.2013)

Imhof, A. E. (1981) Die gewonnenen Jahre. Von der Zunahme unserer Lebensspanne seit dreihundert Jahren oder von der Notwendigkeit einer neuen Einstellung zum Leben und zum Sterben, München: C.H. Beck.

Imhof, A.E. (1987) The extended life course. Reflections on a multidisciplinary European Symposium in Berlin, 26-28 November 1986, in: Medical History, 1987, 31, pp. 440-449.

Johnson, N., Davis, T. and Bosanquet, N. (2000) The epidemic of Alzheimer‘s disease. How can we manage the costs? Pharmacoeconomics. 18 (3), pp. 215-223.

Kitwood, T. (1997) Dementia Reconsidered: The Person Comes First, Open University Press: Buckingham.

Knapp, M. and Prince, M. (2007) Dementia UK (A report to the Alzheimer‘s Society on the prevalence and economic cost of dementia in the UK produced by King‘s College London and London School of Economics). Alzheimer‘s Society: London.

Knapp, M., Comas-Herrera, A., Somani, A. and, Banerjee, S. (2007) Dementia: Summary report for the National Audit Office, London: London School of Economics and Political Science

Lamura, G., Döhner, H. and Kofahl, C. (Ed.) (2008) Family Carers of Older People in Europe. A Six-Country Comparative Study. Hamburg: LIT

Laslett, P. (1991). A fresh map of life: The emergence of the Third Age. Cambridge, MA: Harvard University Press.

Lawton, M.P. and Brody, E.M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. The Gerontologist, 9(3), pp. 179-186.

Lobo, A., Launer, L.J., Fratiglioni, L, Andersen, K., Di Carlo, A. and Breteler, M.M. (2000) Prevalence of dementia and major subtypes in Europe: A collaborative study of population-based cohorts. Neurologic Diseases in the Elderly Research Group. Neurology. 54 (11 Suppl. 5), S4-S9.

Matthews, F.E., Arthur, A., Barnes, L.E. on behalf of the Medical Research Council, Cognitive Function and Ageing Collaboration (2013) A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II. Lancet.

Mace, N.L. and Rabins, P.V. (2001) The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer Disease, Related Dementing Illnesses, and Memory Loss in Later Life (3rd Ed.) Mass Market Paperback.

Mestheneos, E. and Triantafillou, J. on behalf of the EUROFAMCARE group (2005) Supporting Family Carers of Older People in Europe – the Pan-European Background, Hamburg: EUROFAMCARE, University Medical Centre Hamburg-Eppendorf. Available from: www.uke.de/extern/eurofamcare/documents/nabares/peubare_a4.pdf (30.11.2013)

Mooney G. (2003) Economics, medicine and health care. 3rd ed.: Harlow: Pearson Education.

Oeppen, J. and Vaupel, J.W. (2002) Broken limits to life expectancy, Science 10 May 2002: Vol. 296 no. 5570, pp. 1029-1031.

OECD (2012) Health at a Glance: Europe 2012, Paris: OECD Publishing. Available from: http://dx.doi.org/10.1787/9789264183896-en (10.11.2013)

Oliver, M. (1990) The Politics of Disablement. Houndmills: The Macmillan Press.

Pickard, L. (2003a) Chapter 15. Trends in and projections for informal care, in: Comas-Herrera, A. and Wittenberg, R. (2003), p. 180-205.

Pickard, L. (2003b) Chapter 16. Trends in and projections for formal care, in: Comas-Herrera, A. and Wittenberg, R. (2003), p. 206-229.

Prince, M., Bryce,R., Albanese, E., Wimo, A., Ribeiro, W. and Cleusa P. Ferri, C.P. (2013) The global prevalence of dementia: A systematic review and metaanalysis, in: Alzheimer's & Dementia 9, pp. 63-75.

Riedel-Heller, S.G., Busse, A., Aurich, C., Matschinger, H. and Angermeyer, M.C. (2001) Prevalence of dementia according to DSM-III-R and ICD-10: Results of the Leipzig Longitudinal Study of the Aged (LEILA75+), Part I, British Journal of Psychiatry 179, pp. 250-254

Rothgang, H. and Comas-Herrera, A. (2003) Chapter 14: Dependency Rates and Health Expectancy in: European Study of Long-Term Care Expenditure: Investigating the sensitivity of projections of future long-term care expenditure in Germany, Spain, Italy and the United Kingdom to changes in assumptions about demography, dependency, informal care, formal care and unit costs., Report to the European Commission, Employment and Social Affairs DG, London School of Economics, pp. 159-178. Available from: http://eprints.lse.ac.uk/13960/1/DP1840.pdf (27.10.2013)

Rowe, J. W. and Kahn, R. (1997) Successful Aging. The Gerontologist Vol. 37, 4, pp. 433-440.

Schäufele, M., Köhler, L., Teufel, S. and Weyerer, S. (2005) Betreuung von demenziell erkrankten Menschen in Privathaushalten: Potenziale und Grenzen, in: Schneekloth, U. Wahl, H.W. (Ed.) Möglichkeiten und Grenzen selbständiger Lebensführung in privaten Haushalten (MuG III). Repräsentativbefunde und Vertiefungsstudien zu häuslichen Pflegearrangements, Demenz und professionellen Versorgungsangeboten. Integrierter Abschlussbericht im Auftrag des Bundesministeriums für Familie, Senioren, Frauen und Jugend, München, pp. 99-143.

Shakespeare, T. (2006) Disability Rights and Wrongs , London, Routledge.

Tronto, J. C. (1993) Moral Boundaries. A Political Argument for an Ethic of Care. Routledge: New York.

United Nations (2000) Population Division. World Aging 1950-2050. United Nations. Available from: http://www.un.org/esa/population/publications/worldageing19502050/pdf/80chapterii.pdf (07.07.2013)

UPIAS and Disability Alliance (1976) The Union of the Physically Impaired Against Segregation and the Disability Alliance discuss Fundamental Principles of Disability, London.

Wahlbeck, K and McDaid, D. (2012) Actions to alleviate the mental health impact of the economic crisis. World Psychiatry 11, 3, pp. 139-145.

Weyerer, S. (2005) Altersdemenz, (Robert Koch Institut, Gesundheitsberichterstattung des Bundes, Heft 28).

Wimo, A., B. Winblad and L. Jonsson (2010), The Worldwide Societal Costs of Dementia: Estimates for 2009, Alzheimer‘s and Dementia, Vol. 6, pp. 98-103. Available from: OECD iLibrary, Available from StatLink: http://dx.doi.org/10.1787/888932703658 (05.10.2013)

Wimo, A., Jönsson, L. and Gustavsson, A. (2009) Cost of illness and burden of dementia – The base option. Luxemburg: Alzheimer Europe.

Wimo, A., Winblad, B. and Jonsson L. (2007) An estimate of the total worldwide societal costs of dementia in 2005. Alzheimer's and Dementia (3), pp. 81-91.

Wimo, A., Jönsson, L. and Winblad B. (2006) An estimate of the worldwide prevalence and direct costs of dementia in 2003. Dement Geriatr Cogn Disord 21 (3), pp. 175-81.

Wimo, A., von Strauss, E., Nordberg, G., Sassi, F. and Johansson, L. (2002) Time spent on informal and formal care giving for persons with dementia in Sweden. Health Policy 61, pp. 255-68.

Winblad, B., Hill, S., Beermann, B., Post, S.G. and Wimo, A. (1997) Issues in the economic evaluation of treatment for dementia. Position paper from the International Working Group on Harmonization of Dementia Drug Guidelines. Alzheimer Dis Association Disord.11. (Suppl. 3), pp. 39-45.

Winblad, B., Ljunggren, G., Karlsson, G. and Wimo, A. (1996) What are the costs to society and to individuals regarding diagnostic procedures and care of patients with dementia? Acta Neurol Scand Suppl. 168, pp. 101-104.

Wittenberg, R. and Comas-Herrera, A. (2003) Chapter 12. Trends in economic growth and real costs of care, in: Comas-Herrera, A. and Wittenberg, R. (2003), p. 140-147.

World Health Organisation (WHO). (2002a). Active ageing: A policy framework. Available from: http://whqlibdoc.who.int/hq/2002/WHO_NMH_NPH_02.8.pdf (31.10.2013)

World Health Organisation (WHO). (2002b). Towards a common language for functioning, disability and health (ICF). Available from: www.who.int/classifications/icf/training/icfbeginnersguide.pdf (31.10.2013)

Yap, L.K.P., Seow, C.C.D., Henderson, L.M. and Goh, Y.N. (2005) Family caregivers and caregiving in dementia Reviews in Clinical Gerontology 15, pp. 263-271.

Ziegler, U., Doblhammer, G. (2009) Prävalenz und Inzidenz von Demenz in Deutschland – Eine Studie auf Basis von Daten der gesetzlichen Krankenversicherungen von 2002. Rostock, Rostock Center.