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FORMAL AND INFORMAL LONG-TERM CARE AND THE ROLE OF FAMILY CARERS

Czech Republic**

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Formal and Informal Long-Term Care and the Role of Family Carers: Czech Republic: The article discusses developments in long-term care and the availability of support for informal carers in the Czech Republic. Population forecast suggests that the process of demographic ageing in the Czech Republic will accelerate with the ageing of the baby boom cohorts of the 1940s and 1950s. Health and social policy has to address challenges of availability and quality of long-term care, and to develop support services to meet the needs of an ever growing number of older people and their families. The article analyses the long-term care system and the situation of family carers, and explores the challenges to be faced on the way to a more comprehensive long-term care system.

Keywords: long-term care, seniors, family carers, ageing, social and health care services

Die offizielle und Langzeitpflege älterer Menschen in der Familie und die Rolle der Haus- und Familienpfleger/innen in der Tschechischen Republik: Der Artikel beschäftigt sich mit der Entwicklung der Langzeitpflege älterer Menschen und mit den Möglichkeiten der Förderung der

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Haus- und Familienpfleger/innen in der Tschechischen Republik. Laut demografischen Prognosen wird sich der Vorgang der Bevölkerungsalterung in der Tschechischen Republik durch die Alterung der in den 1940er- und 1950er-Jahren des Babybooms geborenen Personen voraussichtlich beschleunigen. Die Gesundheits- und Sozialpolitik sollen Lösungen für die Herausforderungen der Verfügbarkeit und Qualität der langfristigen Altenpflege finden und die Dienstleistungen entwickeln, um die Bedürfnisse der immer mehr werdenden älteren Menschen und deren Angehörigen zu befriedigen. Die Studie analysiert das System der langfristigen Altenpflege und die Situation der Haus- und Familienpfleger/innen und weist auf die Herausforderungen hin, die bei der Erreichung eines umfassenderen langfristigen Altenpflege-Systems auf uns warten.

Schlüsselwörter: langfristige Altenpflege, Senioren, Haus- und Familienpfleger, Alterung, Sozial- und Gesundheitsdienstleistungen

1. Introduction

The issue of population ageing and long-term care for seniors has been gaining visibility in both policy and public debate in the Czech Republic, especially in the context of the capacity, quality and financing of long-term care services. This article focuses on the key characteristics of formal and family care in the Czech Republic and the main trends in social and health care services there.

Long-term care is a specific segment of social protection that includes a variety of support services and combines provision of both health and social care. It includes help with basic activities of daily living (ADL), rehabilitation, medical and nursing care such as help with wound dressing, pain management, medication, health monitoring as well as prevention, rehabilitation, or services of palliative care (COLOMBO et al. 2011; OECD 2005; 2013).

2. Demographic developments in the Czech Republic

An increasing number of the oldest-old seniors with a higher risk of frailty and disability leads to a rising demand for both formal and informal long-term care. At the same time family carers face obstacles and lack of support, which contributes to a growing demand for formal long-term care services. According to the population forecast of the Faculty of Science, Charles University, Prague, demographic ageing will be accelerated by the transition of the cohorts born in the 1940s and 1950s over the next decades and will be faster in the Czech Republic than in other European countries (BURCIN & KUČERA 2010). According to the latest population forecast by the Czech Statistical Office, the share of persons aged 75 years and over will increase from under 7% to almost 17% and their number will increase 2.3 times between 2013 and 2050.¹ The share of people aged 85 and over will increase from less than

¹ Český statistický úřad, 'Úmrtnostní tabulky', life tables of the Czech Statistical Office, retrieved 30 Jun 2015 from the CZSO website, www.czso.cz/csu/redakce.nsf/i/umrtnostni_tabulky.

2% to 6%, and their number will grow 3.5 times. The share of the population aged 65 and over will increase from under 17% in 2013 to over 30% in 2050 (see *Table 1*). Census data show that the number of people aged 95 and over doubled between 2001 and 2011, while the number of centenarians tripled during the same period.²

Table 1
Expected change in the number
and share of selected age groups between 2013 and 2050

	2013*	2020	2030	2040	2050
0–14	1,560,296	1,616,190	1,398,151	1,309,250	1,332,721
0–14 (%)	14.8%	15.4%	13.4%	12.8%	13.3%
15–64	7,188,211	6,744,462	6,570,871	6,182,981	5,656,010
15–64 (%)	68.4%	64.2%	63.0%	60.3%	56.3%
65 and over	1,767,618	2,141,793	2,459,340	2,763,530	3,062,047
65 and over (%)	16.8%	20.4%	23.6%	26.9%	30.4%
75 and over	708,147	861,358	1,298,759	1,470,041	1,663,490
75 and over (%)	6.7%	8.2%	12.5%	14.3%	16.6%
85 and over	168,148	215,252	330,386	544,205	590,346
85 and over (%)	1.6%	2.0%	3.2%	5.3%	5.9%
<i>Total</i>	10,516,125	10,502,445	10,428,362	10,255,761	10,050,778

Source: Population forecast, Czech Statistical Office (see n. 2).

* Actual figures.

Between 1990 and 2000, there was a sharp increase in life expectancy, especially for Czech men (4.1 years compared to 2.9 for women). The development after 1990 is characterised by a ‘cardiovascular revolution’ (Ministerstvo zdravotnictví ČR 2014). The increase continued at a slower pace in the decade between 2000–2010 (2.7 years for men and 2.3 for women). In 2013 life expectancy was 75.2 years for men and 81.1 years for women (see n. 2 and *Table 2*). Despite these developments, life expectancy in the Czech Republic remains below the EU28 average (Eurostat 2015b), and the gap in life expectancy by education is the biggest in the Czech Republic and Central Europe, especially for men (OECD 2012). The increase in life expectancy in health significantly lagged behind the increases in average life expectancy (Ministerstvo zdravotnictví ČR 2014). In 2012 healthy life expectancy at birth (HLY) was 64.1 years for women and 62.3 years for men, and at the age of 65 it was 8.3 years for women and 8.9 years for men (Eurostat 2015a). Between 2005–2013, the gap between total and healthy life expectancy slightly narrowed as healthy life expectancy increased faster (see *Table 2*).

² Český statistický úřad, ‘Výsledky sčítání lidu, domů a bytů 2011’, retrieved 30 Jun 2015 from the website of the Czech Statistical Office, www.scitani.cz.

Table 2
Life expectancy and healthy life expectancy at birth and age 65, 2005–2013

	2005	2006	2007	2008	2009	2010	2011	2012	2013
<i>LE(0) women</i>	79.1	79.7	79.9	80.1	80.1	80.6	80.7	80.9	81.1
<i>HLY(0) women</i>	60.0	59.9	63.3	63.4	62.7	64.5	63.6	64.1	N/A
<i>LE(0)–HLY(0) women</i>	19.1	19.8	16.6	16.7	17.4	16.1	17.1	16.8	N/A
<i>LE(0) men</i>	72.9	73.5	73.7	74.0	74.2	74.4	74.7	75.0	75.2
<i>HLY(0) men</i>	58.0	57.9	61.4	61.2	61.1	62.2	62.2	62.3	N/A
<i>LE(0) – HLY(0) men</i>	14.9	15.6	12.3	12.8	13.1	12.2	12.5	12.7	N/A
<i>LE(65) women</i>	17.6	18.0	18.2	18.4	18.3	18.7	18.8	18.9	19.1
<i>HLY(65) women</i>	6.6	6.8	8.1	7.5	8.1	8.5	8.4	8.3	N/A
<i>LE(65) – HLY(65) women</i>	11.0	11.2	10.1	10.9	10.2	10.2	10.4	10.6	N/A
<i>LE(65) men</i>	14.4	14.8	15.0	15.1	15.2	15.3	15.5	15.6	15.7
<i>HLY(65) men</i>	7.0	7.1	8.4	8.2	8.5	8.8	8.7	8.9	N/A
<i>LE(65) – HLY(65) men</i>	7.4	7.7	6.6	6.9	6.7	6.5	6.8	6.7	N/A

Source: Life tables of the Czech Statistical Office (see n. 2) for life expectancy (LE). European Community Health Indicators (ECHI) – European Commission (Heidi data tool) (Eurostat 2015a) for health expectancy (Healthy Life Years, HLY).

According to the OECD (2014) Czech women can expect to live 10.6 years with activity limitation compared to the EU28 average of 12.7 years, and men 6.7 years compared to the EU28 average of 9.4 years.

3. The increasing demand for long-term care in the Czech Republic

According to *The 2012 Ageing Report* of the European Commission (2012), the number of care recipients is expected to rise to 946,000 in 2060, which is a 50% increase. The report expects the rise especially of users of formal long-term care services as their number will more than double by 2060. Projected long-term care expenditures in the Czech Republic will reach 1.5% of the GDP in 2060. This requires the adaptation of the social protection system to demographic changes and the addressing of potential staff shortages (European Commission 2013).

Epidemiological transition leads to an increase in the incidence of neurodegenerative diseases and a need for long-term care (HOLMEROVÁ et al. 2011; 2012). Other factors contributing to the increasing demand for long-term care include more expensive hospital care and the pressure to shorten hospital stay. Many developed countries have already transferred long-term care for the elderly from hospitals to social services. Concomitantly, a significant portion of the cost was transferred from the health care to the social care budget (MCKEE & HEALY 2002).

As social services are not covered by health insurance, this ‘paradigmatic shift’ has an impact on both persons in need of care and their carers. A further factor is the growing specialisation of medicine, which leaves a number of frail people with complex needs beyond the competence of any specialisation (KALVACH 2008; 2011; KALVACH et al. 2004). The key drivers of rising expenditure can be seen on the supply side, such as the rising costs of new medical technologies. New technology does not necessary mean higher costs, and using new technology can lead to saving, but here I refer to expensive new treatments and drugs rather than to the increasing number of the oldest-old on the demand side (MCKEE & HEALY 2002).

4. The capacity and availability of formal long-term care in the Czech Republic

Similarly to other European countries there is no single long-term care scheme in the Czech Republic. Long-term care is provided under different conditions in the social and health care services (separate registration of providers, financing, quality monitoring and inspection, or personnel standards) (WIJA 2013a; 2013b). The provision of social and health services is regulated especially by the Social Services Act (*Zákon č. 108/2006 Sb.* 2006) and the Health Services Act (*Zákon č. 372/2011 Sb.* 2011).

In the health care system, long-term inpatient health care is provided in different settings: hospitals, facilities for long-term patients, psychiatric and rehabilitation hospitals, and other facilities. Some facilities are also registered to provide social services under the Social Services Act (WIJA 2013a; 2013b). The Health Services Act defines long-term inpatient care as care that is provided to patients whose health condition cannot be significantly improved and whose condition requires complex nursing care.

In the social care system, social services are regulated by the Social Services Act. They are registered by the regional authorities under that Act. People with limited self-care capacity who at the same time receive formal or informal care are entitled to a ‘care allowance’. There are four levels of the benefit corresponding to four degrees of ‘care dependence’. The degree of need for care is determined by an assessment of functional health and ability to perform activities of daily life. The assessment is provided by a physician of the Medical Assessment Service employed by the Czech Social Security Administration and by a social worker employed by the Labour Office. The minimum age of a person who can receive/apply for the allowance is 1 year. The allowance is financed by the state (tax-funded) and is not means-tested. Recipients aged 65 and over make up more than two thirds (68%) of all recipients and 12% of the given age group (see *Table 3*). Recipients of the allowance in Degree I represent 35%; in Degree II, 32%; in Degree III, 20%; and in Degree IV, 13% of all recipients. Since the introduction of the care allowance in 2007 the number of recipients has increased by 35,700 to almost 313,000 in 2012 (WIJA 2013a; 2013b).

Table 3
The number and share of care allowance recipients in selected age groups, 2012

	<i>No. of recipients</i>	<i>Share of all recipients</i>	<i>Share of care allowance recipients within the given age group</i>
<i>Under 65</i>	99,600	32%	1%
<i>65 and over</i>	213,100	68%	12%
<i>75 and over</i>	170,900	55%	24%
<i>85 and over</i>	80,700	26%	48%
<i>Total</i>	312,700	100%	3%

Source: Ministry of Labour and Social Affairs (MPSV 2011a; 2012; 2013).

Critical challenges in formal long-term care include the rise of unregistered providers of residential social care for seniors and people with dementia, uneven quality and standards of health care provided to similar patients in the social and health care sectors (WIJA 2013a; 2013b), and the low availability of community social and health services in small towns, which is crucial in the Czech Republic, where 27% of the population lives in communities of 2,000 or fewer inhabitants (Český statistický úřad 2012, section 1–14). Despite the activity of the Czech Alzheimer Society and broad coverage of the issue of dementia and social services in media, the Alzheimer Plan, which the government declared to prepare, has not yet been adopted (HOLMEROVÁ et al. 2013).

5. The availability of family (informal) care as a supplement to formal care

Informal care plays an important role in the sustainability of long-term care (BÖRSCH-SUPAN et al. 2013). The definition of informal care varies according to specific criteria such as the minimum weekly hours or minimum duration of care provision. Informal carers provide about 70–90% of all long-term care in OECD countries. Most of the care is directed to close relatives, especially parents and partners. Men are more likely to provide care to their spouses than to other persons (COLOMBO et al. 2011). Informal carers are usually women above 50, and their average age is going to increase further (BÖRSCH-SUPAN et al. 2013).

The availability of informal care depends on both macro- and micro-level factors, such as the type of welfare system or exiting the labour market through retirement, deterioration in the household's financial situation, or a change in the household composition. Different welfare systems assign different roles to the family, combining cash and in-kind support. Familialism regimes can be classified as 'im-

plicit', 'explicit', or 'optional'. In explicit familialism regimes the responsibility of care for older individuals is assigned to the family, which receives financial benefits and limited support services, for example in Austria, Belgium, France and Germany. Although such classification is only informative, the Czech Republic or Hungary can be classified as 'explicit familialism' welfare regimes. 'Implicit familialism' regimes primarily encourage family care through a strong normative system, especially in some Southern European countries such as Greece, Italy, Spain or Portugal. 'Optional familialism' is marked by generous professional and financial services and is typical of Scandinavian countries (BÖRSCH-SUPAN et al. 2013).

In the Czech Republic, there are different estimates of informal carers, and the prevalence and intensity of care are not sufficiently explored in research. According to the Ministry of Labour and Social Affairs, there are 250,000 care allowance recipients, of all ages, receiving some form of informal care and using the allowance to pay for informal care exclusively or in combination with some formal social services³ (MPSV 2011a; 2012; 2013) (see *Table 4*). The number does not reveal much about the intensity of informal care. However, about two thirds of care recipients receive first or second degree care allowance, which means they require less intensive informal support and care. According to recent research (JEŘÁBEK 2013) there are about 75,000 seniors in the Czech Republic in the 'intensive care' of their families, and their number is expected to double by 2050. People in need of more care receive third or fourth degree care allowance (see amounts below).

Table 4
Care allowance recipients by type of care received, 2007–2011

	2007	2008	2009	2010	2011
<i>Residential social care</i>	34,500	48,600	55,300	57,200	58,700
<i>Home (domiciliary) social care</i>	10,100	19,300	24,400	24,800	25,700
<i>Informal care (of other person)</i>	209,100	237,100	252,400	254,500	248,400

Source: Ministry of Labour and Social Affairs (MPSV 2011a; 2012; 2013).

However, as the SHARE survey indicates, the extent of exchange of informal support and care is larger. The SHARE data has demonstrated that older people are both giving and receiving support and care (BÖRSCH-SUPAN et al. 2013). According to SHARE (2015), 60% of people aged 80 and above in the Czech Republic say that they have received help from outside the household over the last 12 months, approximately twice as much as in the age group 65–79 years. Nearly one in five

³ Care allowance is paid to the care recipient, and the family/informal caregiver receives it from him or her. The recipient of care allowance is always the person in need of care.

persons aged 80 and above also reported that they had given help to others outside the household over the past 12 months (see *Tables 5 and 6*). The SHARE results indicate geographical patterns in intergenerational provision of help. While giving help to grandchildren or receiving help from children is similar in all European countries, the mean frequency of caregiving is higher in the Mediterranean countries and Poland than in Nordic or Central European countries.

Care allowance presents a significant, often the only, source of income for informal carers, although the allowance is not primarily intended as a reward for informal caregivers but rather as income support for care recipients, enabling them to buy professional social services. There are four levels of the allowance corresponding to the four degrees of ‘care dependence’. The monthly allowance amounts to 800 CZK (appr. €28, Degree I), 4,000 CZK (€144, Degree II), 8,000 CZK (€287, Degree III), or 11,000 CZK (€395, Degree IV). The allowance is higher for recipients under the age of 18. For comparison, in 2014 the minimum wage was 8,500 CZK (appr. €305), the average old-age pension 11,050 CZK (€396) or 12,237 CZK for men (€439) and 10,028 CZK for women (€360).⁴ There is no mechanism of valorisation in the law, and the amount depends on government decision.

Some caregivers thus face problems when the person in need of care (the recipient of the allowance) is hospitalised for an extended period, for allowance payment is suspended for the period of hospitalisation if it exceeds one month.

Table 5

The share of respondents in the Czech Republic who reported having received help from outside the household over the past 12 months, by age and gender

<i>Received help from outside the household</i>	<i>Age group</i>				<i>Total</i>
	<i>Under 50</i>	<i>50–64</i>	<i>65–79</i>	<i>80 and over</i>	
<i>Male</i>	29%	20%	27%	49%	26%
<i>Female</i>	17%	25%	37%	67%	33%
<i>Total</i>	18%	23%	33%	60%	30%

The period of providing informal care to a recipient of second, third or fourth degree allowance is considered by law as ‘non-contributory periods of insurance’ (*Zákon č. 155/1995 Sb.* 1995). The carer is thus considered as employed for the purposes of old-age pension. However, reduced income during informal caregiving is not compensated for in pension income. Informal carers in the Czech Republic, similarly to other European countries, have lower income and face difficulties in the labour market (COLOMBO et al. 2011). In the Czech Republic about 59% of caregivers stated that they had to interrupt or leave their employment, which can trigger early

⁴ As of 11 Jan 2015, the exchange rate was €1 = 27.87 CZK.

retirement. One in twenty economically inactive pensioners states that the cause of retirement was the loss of job and the inability to find a new one. Family/informal carers in the Czech Republic may face multiple discrimination as carers, people over 50 and women (SOKAČOVÁ 2014)

Table 6

The share of respondents in the Czech Republic who reported having given help to others outside the household over the past 12 months, by age and gender

<i>Gave help to others outside the household</i>	<i>Age group</i>				<i>Total</i>
	<i>Under 50</i>	<i>50–64</i>	<i>65–79</i>	<i>80 and over</i>	
<i>Male</i>	43%	35%	27%	23%	31%
<i>Female</i>	44%	37%	26%	15%	31%
<i>Total</i>	44%	36%	27%	18%	31%

Source: SHARE 2015.

The carers of people with dementia face special challenges. There are currently some 140,000 people with dementia (HOLMEROVÁ et al. 2013). Up to 80% of the people with Alzheimer's or another form of dementia receive care from family at home in the Czech Republic (HOLMEROVÁ 2003; HOLMEROVÁ et al. 2006). People who care for people with dementia often perceive themselves as overburdened. For many carers the demands of daily care exceed their emotional capacities (SCHINDLER et al. 2012). According to European studies, up to 78% of caring partners and 47% of adult children are suffering or have suffered from depression (MPSV 2011b). Caregiving significantly interferes with their family relationships. People with dementia receive the care allowance. However, there seems to be some bias in the assessment of cognitive impairment. Evaluation design is focused on physical disability and ADL, while people with dementia lose independence in IADL, and dementia is underdiagnosed in both institutional populations and the general population (HOLMEROVÁ et al. 2013).

6. Reflections

The quality of formal long-term care system has substantially improved over the last years with investments in the life-long education of workers and other initiatives. The residential capacities in social services have increased, while the availability of health care and health staff in such facilities as homes for seniors remains a challenge. In recent years there have been attempts to adopt legislative reform of long-term care to define the relationship between health and social sectors in order to ensure interdisciplinary long-term care (MPSV 2011b). However, the reform regu-

lating interaction and cooperation between health and social services has not yet been adopted.

The availability of support for family carers and ageing at home remains fragmented, insufficient and geographically uneven, especially in smaller towns which hugely rely on informal support. The main reason and 'motive' for caregiving is a combination of emotional relationship and moral obligation. Awareness of the needs of family carers is increasing, and more and more residential and in-home social services provide respite care as well. In addition to the low availability of support and services for informal carers, the unaffordability of paid services is a barrier for care seekers as the price of services is considered high. Moreover, in small towns and villages the use of professional home care is often perceived as socially stigmatising for the family. The preference for home care over residential care is also stronger in small towns. As informal carers often face financial stress, the low availability of flexible working arrangements, such as part-time jobs or work from home, remains a substantial problem and barrier for informal carers.

Patients' organisations and NGOs doing advocacy for frail seniors and their carers play an important role in policy changes and in raising public awareness of the issue. The challenge remains timely, however, and a system of coordinated social and health care, of integrated outpatient, in-home and respite services, and an adequate support system for informal carers are still goals to achieve. Despite all difficulties, the number of initiatives, training courses for carers, information and awareness projects has increased over the past years.

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