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TRANSITION OF LONG-TERM CARE IN HUNGARY

Problems and Solutions

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The study presents the challenges of long-term care for the elderly from 1993 to the present, which arise from the poor state of health of the population over 65. It analyses the related trend in policy on the elderly, how a positive trend up to 2008 took a negative turn. Against this background, it examines the role family carers play in caregiving. Their task has become increasingly difficult as a result of the state shifting responsibility to the families, strong demographic ageing and the appearance of declining health in an early stage of the life cycle. Alternative solutions must be found to relieve this burden, and one possible direction is the incorporation of ICT into long-term care. The study presents innovative solutions facilitating care: the WebNurse developed for family carers and Skype Care to ease the loneliness of the elderly.

Keywords: ageing, long-term care, family carer, infocommunication (ICT), innovation

Wandlung der Langzeitpflege älterer Menschen in Ungarn: Probleme und Lösungen: Die Studie zeigt die Herausforderungen von 1993 bis zum heutigen Tag, mit denen sich die langfristige Altenpflege wegen des schlechten Gesundheitszustandes der Menschen über 65 Jahre konfrontiert sieht. Die Studie analysiert den damit verbundenen Trend in Bezug auf die Altenpolitik, wie sich die positive Entwicklung bis zum Jahr 2008 in einen negativen Trend verwandelte. In diesem Rahmen werden die Folgen der Verantwortungsabwälzung des Staates erörtert. Bei den älteren ungarischen Menschen treten die Verschlechterung der Funktionen und der schlechte Gesundheitszustand bereits in einer früheren Lebensphase auf, gleichzeitig steigt die Lebenserwartung, was die Erhöhung der mit Krankheiten verbrachten Jahre bedeutet, das heißt den Familien fallen immer längere und schwierigere Pflege- und Betreuungsaufgaben zu. All das erfordert die Entwicklung von alternativen Lösungen, die die Pflege erleichtern. Eine mögliche Richtung ist die Anpassung der Informationskommunikation an die Langzeitpflege für ältere Menschen. Die Studie präsentiert Lösungen, welche die Pflege erleichtern: die speziell für die Haus- und Fami-

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lienpflegerinnen entwickelte „WebPflegerin“, bzw. auch das für Familien geeignete Skype Care, das eine Lösung für die Einsamkeit älterer Menschen darstellen sollte.

Schlüsselwörter: Alterung, langfristige Altenpflege, Haus- und Familienpfleger, Information und Kommunikation, Innovation

1. Healthy ageing and care in Hungary and Europe

The proportion of the population over 65 years of age increased substantially in Hungary between 2002 and 2013 from 12.4% to 13.1%,¹ and that of the 80+ age group from 2.9% to 4.1%.² In 2012 life expectancy for men over 65 was 14.3 years, and for women 18.1 years,³ but the healthy life years (HLY) expectancy fell far below that level to only 6.4 years for both men and women, indicating considerable care needs, especially in the case of women, who can expect a much longer period with restricted functions, 11.7 years compared to 7.9 years for men. The figures are much lower for both sexes than in the majority of the EU countries (Eurostat 2015); the appearance of declining health in an early stage of the life cycle represents an especially serious problem. According to the most recent census (2011), 40% of those over 60 (more than 900,000 persons) have a chronic illness in Hungary; more than one in ten are restricted in caring for themselves, one third in their everyday life and more than one quarter in the use of transport. A further 11% of those over 60 live with some form of disability (physical disability, impaired sight, impaired hearing) (KSH 2014). On the other hand, long-term care expenditure as a share of the GDP is very low, less than 0.5% with lower levels found only in Estonia, Portugal and Greece among the OECD countries. The difference compared to the Netherlands and Sweden is especially striking (3.8% and 3.6%, respectively, in 2011).⁴ This is not exclusively related to the more cost-intensive illnesses occurring in old age, but also to the fact that these countries have recognised the challenge of long-term care and developed a policy to deal with it (OECD 2013).

EU ageing policy places emphasis on active ageing, and this concept has recently been extended to include the life stage spent in long-term care. In this interpretation, improving the quality of life of the elderly within a complex system incorporating the following elements is of key importance: coordination of the health and social sectors, creation of interlinked forms of service, reconciliation of work and care, a suitable financing structure, creation of a suitable environment,

¹ This is the same as the average of the EU28.

² 'Népesség korcsoportonként (2003–2014)', Eurostat data table, retrieved 28 Apr 2015 from the website of the Hungarian Central Statistical Office, www.ksh.hu/docs/hun/eurostat_tablak/tabl/tps00010.html.

³ '65 éves korban még várható élettartam, nemenként (1990–2012)', Eurostat data table, retrieved 13 Apr 2015 from the website of the Hungarian Central Statistical Office, www.ksh.hu/docs/hun/eurostat_tablak/tabl/tsdde210.html.

⁴ The OECD average is 1.8% with Norway, Denmark, France, Belgium, Japan and Iceland between 1% and 1.5%.

easing the life of the elderly based on ambient assisted living and the introduction of solutions making use of ICT, the elaboration of other solutions enhancing the activity of informal carers, especially family carers, launching technical and medical-biological research aimed at reducing the need for long-term care, the involvement of civil and nonprofit actors in problem-solving, creating suitable communication, and in general, the exploration of new potential within frameworks supported by the EU.⁵ The European Union gives attention to programs developed at the regional, local government level in different countries, and to presenting good examples (OLSSON 2014). All this reflects a growing positive trend in the EU countries in facing the challenge of long-term care. Hungary has moved in the opposite direction; to understand the reasons we need to consider the milestones in the legislation of long-term care between 1993 and 2015.

2. The trend in long-term care in Hungary, 1993–2015

Replacing the earlier poverty principle, the Social Welfare Act of 1993 (*1993. évi III. törvény*) made it mandatory for local authorities to provide home care (for a maximum of 4 hours a day) and meals for persons over 60 in a normative-based financing system. It required towns with over 2,000 inhabitants to operate what is called a seniors' club (providing meals, activities, personal hygiene) as a specialised service. The service could also be provided by NGOs, churches or the private sector. The hard standards of the 1994 regulation (e.g. sqm/person in residential homes, *2/1994. (I. 30.) NM rendelet, 9/1999. (XI. 24.) SzCsM rendelet*) resulted in further qualitative improvement, but small towns and disadvantaged regions were unable to meet the requirements and provide basic services. An examination by the State Audit Office in 2004–2005 clearly showed that the reason why home care coverage stood at only 66.6% (Állami Számvevőszék 2007) was post-payment financing.⁶ In 2009, 75% of towns with fewer than 400 inhabitants were able to provide home care, and 70% meals (KSH 2011, 1–3). In 2006 the model of home care with emergency alarm developed by HCSOM in 1992–1994 was incorporated into the Social Welfare Act (*1993. évi III. törvény*). The organisation became a Centre of Methodology with the right to monitor and train.

A negative trend began in 2008 (*36/2007. (XII. 22.) SZMM rendelet, 340/2007. (XII. 15.) Kormányrendelet*). In that year the methodological authorisation was withdrawn from the organisation. In 2009 the budget provided for the emergency alarm system was reduced from the earlier (2006) level of 4 million EUR to 3.6 million EUR, and in subsequent years this amount was further reduced despite growing demands. Another measure with a negative impact in the same period was that only

⁵ MOPACT (2013–2017) Mobilising the potential of active ageing in Europe. European Commission under the 7th Framework Programme: <http://mopact.group.shef.ac.uk/> (accessed 10 Mar 2015).

⁶ In 2004, 3% of all persons over 60 received home care; 5% meals on wheels; 2% attended clubs for the elderly; home nursing was provided for 0.4% (PAPHÁZI 2005).

towns with more than 3,000 inhabitants were required to operate a seniors' club. That meant the elimination of 8% of towns from this provision (Állami Számvevőszék 2007). In the case of residential homes the threshold for mandatory provision was raised from 10,000 to 30,000 inhabitants. The conditions for admission to a residential home were also changed. Only persons requiring over 4 hours of care a day could be accepted, thereby shifting the care towards nursing without providing the necessary health services or strengthening home care. Home nursing that could be provided for two weeks (financed by the Health Fund) solved only the problem of acute need for health care, and did not constitute a supplement to long-term home care in the social sphere. The ministry's obstacle-free model program between 2003–2005 represented a slight positive change (SZÉMAN & PÖTTYÖNDY 2006). On the basis of an invitation for tenders announced by the ministry, the possibility arose to extend the program to a wider target group of persons receiving care at home, but in subsequent years it was discontinued. By 2012 the formal care system was struggling with serious problems of quantity and quality. The number of persons receiving home care increased threefold between 2000 and 2012 (from 40,212 to 125,281), but this was not followed by a similar increase in the number of carers. The net result was a upsurge in the number of recipients of care per carer: from 4.3 elderly persons per carer in 2000 to 7.3 by 2011 (KSH 2012, Table 7.3). Such a workload made it impossible to provide the four hours of care a day allowed under the law. The following dilemma arose: to provide less intensive care, or to offer more intensive care in which case some elderly persons would not be included in the system, and the care burden on families would increase. The Fundamental Law (Constitution) of 2011 further exacerbated the trend of shifting the burden of care to the families by enjoining the duty of caregiving on them. In 2015 the threshold score in the system of rating the state of physical and mental health was raised, thereby pushing home care in the direction of nursing without providing the necessary resources, and simply leaving families to shoulder a new care task.

Table 1

1993	<p>Social Welfare Act (1993. évi III. törvény):</p> <ul style="list-style-type: none"> – home care and meals on wheels for people over 60 years are basic mandatory task of local government; – towns with over 2,000 inhabitants must operate clubs for pensioners that provide meals and activities preventing mental decline; – towns with over 10,000 inhabitants must operate a residential home; – possibility for temporary care (for up to 1 year); – nursing allowance, with automatic entitlement in case of care given in the home to a child or adult with serious disability, or to an older person.
1994	Two weeks of home nursing financed by the Health Fund.
1994	Regulation defining the quantitative and qualitative criteria of services and the professional tasks and operating conditions of institutions providing personal care (2/1994. (I. 30.) NM rendelet).
2000	Further development of the professional tasks and operating conditions of institutions providing personal care (1/2000. (I. 7.) SzCsM rendelet).
2006	<p>Addition of a new service under the Social Welfare Act (1993. évi III. törvény):</p> <ul style="list-style-type: none"> – inclusion of the emergency alarm system into home care for the elderly; – Hungarian Charity Service of the Order of Malta (HCSOM) set up a centre of methodology. The organisation developed the service into a model program between 1992–1994.
2008	HCSOM was authorised to operate the National Centre of Methodology.
2008	<p>Change in conditions for services linked to population size:</p> <ul style="list-style-type: none"> – club for the elderly to be maintained by towns with over 3,000 inhabitants (as opposed to the earlier 2,000); – residential home mandatory in towns with over 30,000 residents.
2009	Change in conditions for admission to a residential institution: persons must require 4 hours of care a day (as opposed to 2 hours earlier).
2009	Decrease in the budget for emergency alarm.
2011	New Constitution declares care to be a family task.
2013	Centralisation of home care with emergency alarm.
2013	Decrease in the financing of home care.
2015	Criteria for receiving home care become stricter.

3. The role of families in care

Since 2004 the problem of family care has occupied an increasingly prominent place among EU research projects (e.g. EUROFAMCARE 2003–2005 and CARICT 2011).⁷ It is well known that in the EU some 19 million family carers spend more than 20 hours a week on caregiving and more than half of them devote at least 35 hours to caregiving (COLOMBO et al. 2011). In some countries care is an especially big burden on families. According to BŁĘDOWSKI and colleagues (2004) in Poland more than 2 million family carers spend 100 hours a week on caregiving, which means an extremely intensive care. At the same time in Hungary, apart from estimates and a qualitative investigation by the Hungarian Charity Service of the Order of Malta, there are no representative figures on family carers providing care for people living with a serious illness or in need of lengthy rehabilitation. According to the estimate made by the Centre of Methodology, in the 2000s some 400,000 persons over 65 lived with various degrees of (severely) reduced function, but only 170,000 of them received some form of health or social care, while 230,000 persons received none. They were not in residential homes, in hospital or nursing wards, in chronic internal wards, or in the social home care system, but they might have been cared for by family/informal carers, risking a negative effect on the life of the carers.⁸

The findings of qualitative research on family carers based on 18 in-depth interviews by the HCSOM Centre of Methodology in 2011 show the negative effects of caregiving on the carer. The majority of family carers in the sample lived far away from their relatives (even in the same town) and very often had to provide intensive care even if their relatives received care in the public sector. The need to leave the workplace in case of an emergency and then having to work overtime to make up for time spent away from the job caused stress for almost all of them, producing somatic symptoms in many cases, hastening the deterioration of their own health, and making them potential care-receivers.

There is a growth in the care burdens of family carers on the one hand, and on the other hand, the Fundamental Law (Constitution) made caregiving an obligation of families without providing the necessary means of support. The nursing allowance is an automatic entitlement for full-time carers of disabled children or adults with serious disability, but the allowance can be awarded to those caring for elderly persons only on the merits of the case, and cost-saving considerations prompt local governments to withhold such support. According to the latest figures available, there was a steady increase in the number of supports based on automatic entitlement between 2000 and 2012 and a decline in supports based on merit over the same period. The former grew nearly fivefold, from 8,456 persons in 2000 to 47,458 in

⁷ EUROFAMCARE (2003–2005): Supporting Family Carers of Elderly People in Europe: Characteristics, Coverage and Usage. The National Background Reports can be read on the website of the project EUROFAMCARE: www.uke.de/extern/eurofamcare/publikationen.php?abs=2 (accessed 10 Mar 2015). Further on the project CARICT (2011), see CARRETERO et al. 2012.

⁸ Oral interview with Zoltán Tarnai (2015), head of the HCSOM Centre of Methodology.

2012. While the number of persons receiving the nursing allowance based on the merits of the case increased until 2005 (20,540 persons), by 2012 their number had fallen by half (to 10,514) (KSH 2012, 89–90, Tables 6.7–6.8). These figures also clearly indicate the negative trend in the policy on the elderly from the second half of the 2000s on, irrespective of which party is in power.⁹ At the same time, starting in 2011 a process was initiated by researchers, the civil sphere and local governments wishing to confront this situation by developing model programs based on innovation, the exploration of the possibilities of ICT and the mobilisation of new human resources.

4. New turning point

4.1. WebNővér

Family and informal carers without suitable care and nursing skills have to carry a big burden in long-term care in Hungary as the state gradually began to withdraw. To answer the challenges and ease this situation, in the framework of the HELPS project of the Central European Programme of the European Union, the Hungarian Charity Service of the Order of Malta (HCSOM) drawing on earlier research began to elaborate and test a web-based pilot program called WebNővér (WebNurse; www.webnover.hu), which comprises six elements: 1. short explanatory videos teaching nursing tasks, 2. service map, 3. mental support, 4. nutrition advice, 5. care advice, 6. legal advice (*Report on Pilot Findings* 2014, 24–26). Access is free, ensuring quick dissemination. The pilot program was presented to the media, governmental and local decision-makers, experts and a wider audience in January 2014. Since then it has begun to spread and raise awareness of how a web-based solution can help family carers and informal helpers.

4.2. Skype Care

Another model program started in 2011 targeted lonely, depressed, digitally illiterate persons over 75 years of age receiving care because of their deteriorated physical and mental state. It covered different settlement types (Budapest, a big town, a small town and villages) and involved 50 persons with an average age of over 80 years and various levels of schooling. Its aim was to demonstrate that the loneliness and isolation of the frail, lonely elderly can be overcome by teaching them the use of Skype. Sick elderly persons in need of care are usually regarded as incapable of acquiring digital skills¹⁰ – an understandable prejudice in view of the 2008 statistics: even

⁹ 2002–2010: Socialists/Free Democrats; since 2010: FIDESZ/Christian Democrats.

¹⁰ The findings of an MSW student's 2015 study based on in-depth interviews with 23 general practitioners in Budapest confirm the continued existence of this prejudice. The majority of interviewees considered their elderly patients incapable of acquiring technical skills of any kind.

among those aged 65–74 years barely more than 5% used the internet (KSH 2009a; 2009b). However, the program hypothesised that the very elderly in need of care are capable of learning if they are taught by young people aged 14–16 years in possession of up-to-date ICT skills and still free of prejudices. Within a very short time, already by the sixth month, old people were learning to use Skype, something entirely new to them, as they had the motivation to use video communication particularly with their grandchildren. Their earlier restricted contacts gave way to expanding interpersonal connections. By using the internet, they were not only able to acquire new knowledge, but the daily occupation also kept them busy, and their loneliness disappeared. The program also revealed a previously underutilised new human resource, secondary school students who taught the elderly, first as an experimental element in 2011 then as a regular arrangement from 2012, when voluntary service was incorporated into the school curriculum. Through their voluntary activities the ICT knowledge gap between the youngest and the oldest generation was bridged, which also helped foster closer intergenerational contacts (SZÉMAN 2012).

4.3. Complex care for the elderly

In 2013 a representative survey of 25,000 elderly persons explored what kind of services they needed to enable them to continue living at home for as long as possible. The demand for *company* expressed by 76% of the interviewees exceeded the 67% demand for primary and specialised health care. Further typical answers included board games mentioned by 15% and someone to read aloud for them, mentioned by 16%. These answers can and must be interpreted as ways to counter loneliness. Similarly, walking in groups (mentioned by 49%) cannot be categorised under either social or health care services.¹¹ Taken together, the findings drew attention to loneliness as a social problem (JENEINÉ RUBOVSKY 2014).

In response to those findings, a model program of virtual care was launched in the spring of 2015 in Budapest's 5th district and in Kisvárdá, a town in North-Eastern Hungary. It is financed by the Ministry of National Development but participating institutions also include the Ministry of Human Resources and the Ministry of Interior. Workers of a care centre are in virtual contact with elderly persons receiving care. Participants are provided with a personal alarm bracelet, a computer and a smartphone by the Ministry of Human Resources. The virtually provided care is mental care, including regular virtual visits, conversation and games. In the future, services offered by the centre will be expanded to include help for family members caring for the elderly. They will include the creation of a database, information, advice. The centre is in regular contact with the elderly persons' home carers, informing them of their clients' needs.

¹¹ The other categories included: meals (32%), manicure/pedicure (32%), spring cleaning (24%), home assistance (24%), exercises to improve physical movement (14%), help through the home emergency alarm system (12%), help with official affairs (10%), hairdresser (4%), care of the yard/garden (1%).

In the Skype Care program, secondary school students teach computer skills to the elderly. Another new human resource in caregiving may be persons participating in the public work program. This program was introduced by the government as a way of dealing with unemployment. Participants in the program can be trained to acquire caring skills, and the public workers' involvement in virtual care may create a possibility to return them to the labour market. In addition to making use of the possibilities offered by ICT, the model program thus also draws on human resources not previously used in care: secondary school students and persons in the public work program.

5. Reflection

The brief survey above throws light on the positive trend that began with the 1993 reform and lasted up to 2008, but then gradually gave way to an increasingly strong trend of withdrawal by the state. After the downward turn, new research based on the initiatives of local governments and non-governmental agencies appeared in which actors from below developed model programs making use of ICT and sought ways to incorporate them into care. 2015 has seen the simultaneous beginning of a negative and a positive trend. The stricter conditions for inclusion in home care without the provision of adequate resources definitely need to be changed as has apparently been realised at the macro level as well. At the same time, with the appearance of a new factor we have reached a milestone, and spring 2015 must be regarded as a turning point in home care for the elderly in Hungary. For the first time in recent history, three ministries have made a coordinated effort to improve care for the elderly: the ministry responsible for technical innovation is financing the program, the Ministry of Human Resources assumes responsibility for the home care of older people in the program, and the Ministry of Interior responsible for the public work program is also a partner. This cooperation underlines the importance of the recognition that care for the elderly must move beyond an exclusively social approach. In 2015 we are witnessing a new complex policy on the elderly that points in the right direction and is expected to have a positive effect in the near future.

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