

New measure to assess the unmet needs for long term care using SHARE data

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Abstract

In the article we provide a new measure / scale to assess the unmet needs for long term care, based on SHARE data. Using 5th wave of SHARE data on ADL limitations we are able to prepare estimates of the number of persons 50+ with informal care or with unmet needs. But the existing data do not provide any information on the intensity of the declared limitations performing of daily living and thus categorization of these persons using the Care Dependency Scale. As the beneficiary must have at least one ADL limitation we decide to develop a limited assessment scale based on all 6 ADL activities and use it for the categorization of persons with informal care or unmet needs. Results obtained were compared with the results from the triage process for formal home care and first, rough, estimate of possible additional beneficiaries was done. Finally, a validation of the measure using econometric modelling was provided confirming a significant advance in the modelling terms when compared to the previous, more general classification.

Introduction¹

Slovenia is in the long-term process of preparation a completely new Long term care system. In accordance with the conclusions adopted by the Slovenian Government in September 2013, the key assumption of the new regulation is, in addition to ensuring a sustainable financing system, that it should enhance the formal and informal forms of care at home/community, and

¹ "This paper uses data from SHARE Waves 1, 2, 3 (SHARELIFE), 4 and 5 (DOIs: 10.6103/SHARE.w1.500, 10.6103/SHARE.w2.500, 10.6103/SHARE.w3.500, 10.6103/SHARE.w4.500, 10.6103/SHARE.w5.500), see Börsch-Supan et al. (2013) for methodological details.* The SHARE data collection has been primarily funded by the European Commission through FP5 (QLK6-CT-2001-00360), FP6 (SHARE-I3: RII-CT-2006-062193, COMPARE: CIT5-CT-2005-028857, SHARELIFE: CIT4-CT-2006-028812) and FP7 (SHARE-PREP: N°211909, SHARE-LEAP: N°227822, SHARE M4: N°261982). Additional funding from the German Ministry of Education and Research, the U.S. National Institute on Aging (U01_AG09740-13S2, P01_AG005842, P01_AG08291, P30_AG12815, R21_AG025169, Y1-AG-4553-01, IAG_BSR06-11, OGHA_04-064) and from various national funding sources is gratefully acknowledged (see www.share-project.org)."

that the institutional form of long-term care will be provided primarily to persons who need the largest amount of care or have complex and combined needs.

Objectives of the new law, which will regulate the long-term care and personal assistance, are as follows:

- The introduction of a solidarity financing of long-term care on the principles of social insurance and secured financially sustainable system of long-term care;
- Promoting access to quality, individualized services and rights of long-term care for the entire population who needs these services, giving priority to those forms of assistance and support provided to beneficiaries that remain in their home environment;
- Achieving greater efficiency and transparency of funds that are invested in long-term care;
- Linking formal and informal long-term care providers in a functionally integrated, rational and efficient system;
- Systematic development of preventive action and promote the rehabilitation and the use of modern information and communication technologies in the field of long-term care;
- Harmonization and simplification of procedures in relation to the assessment of individual needs/rights for services arising from long-term care and personal assistance;
- Providing support for people with disabilities in the implementation of those activities related to integration into society, which are, due to the hardest types and levels of disability, unable to provide them by themselves;
- Promoting individual responsibility and his family to provide appropriate levels of care and assistance or social security at a time when they are dependent on the help of others.

Estimation of the number of beneficiaries, who will have rights under the new legislation, is based on the assumption that all possible beneficiaries will be included in a single triage process within which the degree of care dependency for various day tasks will be determined.

A special working group performed triage on a representative sample of users of various types of long-term care (Poljšak, V. et al, 2014). The aims were the following ones: a) estimation of the level of self-care using the Care Dependency Scale – CDS (Dijkstra A., 1998) b) determination the entry threshold and the number of persons who would have entered into the system and c) determination of the range of services that will be provide to beneficiaries under the new legislation.

Based on the results obtained generalized estimation of the number of beneficiaries was prepared (MLFS, 2015). Its main deficiency was that it did not take into account also possible additional beneficiaries coming from the group of persons with informal care or persons with unmet needs. Using 5.wave SHARE data on ADL limitations we were able to prepare estimates of the number of persons 50+ with informal care or with unmet needs (question ph049; Börsch-Supan, A. , 2016). But, the data did not provide any information on the

intensity of the declared limitations performing basic activities of daily living and thus categorization of these persons using the Care Dependency Scale. As the beneficiary must have at least one ADL limitation we decided to develop a limited assessment scale based on all 6 ADL activities (compared to 15 dimensions used in CDS) and use it for the categorization of persons with informal care or unmet needs. Results obtained were compared with the results from the triage process for formal home care and their quality has been further evaluated using commonly used Heckman's two-step selection econometric models (for more see e.g. Gannon and Davin, 2010).

Data

Existing proposal of a new system of long-term care with an entry threshold and the possibility of receiving a certain amount of money for organizing home care raises the question of the number of beneficiaries with informal care at home or even persons with unmet needs, who could enter into the new system of long-term care. First, we should start with the estimation of the number of beneficiaries with informal care or persons with unmet care. In assessing the number we used data of 5th wave of infrastructure databases produced in the framework of the International Project SHARE on ADL and/or IADL limitations (question ph049; Börsch-Supan (2016). In the second step we tried to estimate the number of persons who would be eligible to enter into the new system of long-term care using the adapted Care Dependency Scale. For this step a set of different data bases were used: estimated care dependency data for 2012 and 2014 obtained for persons included in institutional care, home care and community care (Poljšak et al., 2014 and internal databases) and data on standardized time used for nursing services, rehabilitation, physiotherapy and social care for the same beneficiaries in institutional care.

As categorization on CDS and testing for care services obtained by each beneficiary in the sample were not directly linked and the CDS does not have any information about the set and the volume/time of services for each particular category of care dependency, we linked both databases – more than 300 different services, together with their standardized times, were linked to all 15 dimensions of care dependency and to additional two dimensions (“other health services” and “other common care services”).

Methodology

For the estimation of the number of persons with informal care or unmet needs we used the following assumptions: a) firstly, we took into account all persons who affirmed that they had informal care or persons who have at least one limitation in performing basic activities of daily living while receiving no formal or informal care; b) secondly, we limited our analysis to the persons who had informal care almost every day and had at least one ADL limitation, c) thirdly, with the help of adapted CDS, we estimated the number of persons with informal care or with unmet needs that would be eligible to enter into the formal new long term care system and d) finally, we tested the quality of the adapted CDS using the data for all SHARE countries that participated in the 5th wave using Heckman's two step selection model and information criteria (AIC and BIC).

The scale for assessing care dependency was developed in the Netherlands in 1998 (the Care Dependency Scale - CDS A. Dijkstra, 1998). Care dependency has been described as "The professional support to a patient whose self-care abilities have decreased and whose care demands make him/her to a certain degree dependent. The aim of the support is to restore the patient's independence in performing self-care (Dijkstra et al., 2006, p.5). As care dependency can be seen as variable in intensity, it was decided to develop an assessment scale and to measure each of the 15 dimensions of care dependency on a five-point Likert-scale ranging from 1 (completely care dependent) to 5 (completely independent) (Dijkstra et al., 1998a). The scale is based on Virginia Henderson's framework of 14 human needs (V. Henderson, 1966, 1978, and 1985).² The CDS represents an aid to assessing patient's needs and the degree of professional assistance required to meet these needs. Repeated assessments with the CDS provide information for monitoring changes in patient status and, potentially, assessing the success of interventions in decreasing patient's dependency (Dijkstra et al, 2006, p.7).

The CDS is therefore not intended to be used for the assessment of the eligibility of particular person to enter into the system of formal long-term care based on the specified time threshold of needed services. There is no code list of services and no standardized time for services needed for each category within all 15 dimensions of care dependency. This does not mean that the CDS cannot be used for this purpose but the scale should be appropriately supplemented with missing information.

CDS translated into Slovenian language preserves the five-level Likert scale about the care dependency but with the reversed levels and following the basic text (Dijkstra et al, 1998a) as regards the five level Likert scale (from completely care dependent (5) to completely care independent (1). As the existing proposal of a new system of long-term care uses an entry threshold (certain number of hours of care services during one week) using only the categorization of beneficiaries with CDS scale would be of limited applicability. Consequently, we linked the data on standardized time used for nursing services, rehabilitation, physiotherapy and social care for the same beneficiaries in institutional care with the 15 dimensions of care dependency and additional two categories in order to be able to use the data of complete set of care services.

Using 5.wave SHARE data on ADL and/or IADL limitations we were able to prepare estimates of the number of persons 50+ with informal care or with unmet needs. But, the data did not provide any information on the intensity of the declared limitations performing basic activities of daily living and thus categorization of these persons using the Care Dependency Scale. As the beneficiary must have at least one ADL limitation we decided to develop an adjusted assessment scale based on all 6 ADL activities with the total possible number of points from 6 to 30 (compared to 15 dimensions used in CDS and the number of points from

² Translation of Henderson's 14 human needs in nursing care dependency items of nursing care (adopted form Henderson, 1966) can be found in Dijkstra et al, 1998a, p. 148, Figure 1. It has to be pointed out that in the Manual Care Dependency Scale the authors changed the range of the five-point Likert-scale from 1 (completely care dependent) to 5 (almost independent) (Dijkstra et al, 2006, p. 5).

15 to 75) and use it for the categorization of persons with informal care or unmet needs with the use of additional information about GALI indicator³ and health index⁴.

Using the estimated health index for the selected persons who received informal care almost every day and had at least one ADL limitation, and persons who declared to have at least one ADL limitation but did not receive any formal or informal care (persons with unmet needs), we formed quintiles. In the next step we combined GALI indicator (whether a person had severe limitations or not) and attained quintiles of health index to be able to estimate the average category (1-5) of selected persons. This, average category was then assigned to every declared ADL limitation of particular selected person. Finally, based on the points gathered, we were able to estimate the category of care dependency.⁵

As a robustness check and validation of the new measure we performed the Heckman's two step selection models, using two types of constructed variables for "need" – when the need consists of those in the full CDS scale (need5) and when it consists of those in the limited CDS scale with values from II-V (need4). On the basis of those two variables we also construct two different variables of unmet needs – unneed4 and unneed5.

The model we estimate is, therefore:

The Heckman's selection model (Gronau 1974; Lewis 1974; Heckman 1976) assumes that there exists an underlying regression relationship (the regression equation):

$$y_j = x_j\beta + u_{1j} \quad (1)$$

The dependent variable, however, is not always observed. Rather, the dependent variable for observation j is observed if (the selection equation):

$$z_j\gamma + u_{2j} > 0 \quad (2)$$

where:

$$u_1 \sim N(0, \sigma)$$

$$u_2 \sim N(0, 1)$$

$$\text{corr}(u_1, u_2) = \rho$$

Results

In the first step we considered all persons who received only informal home care –the estimates show that 104 thousand persons older than 50 years fulfilled this criteria (for the

³ Exhaustive analysis of dependency indicators (ADL, IADL, GALI and functional limitations) can be found in Zver and Srakar (2015).

⁴ Health index has been calculated using the procedure of Hendrik Jürges (2015).

⁵ Categories of care dependency for this adjusted CDS are the following: category 1 (6-10 points), category 2 (11-15 points), category 3 (16-21 points), category 4 (22-26) and category 5 (27-30 points). For each declared ADL limitation particular person gets appropriate number of points (1-5) and 1 point for each remaining ADL limitation.

year 2013, or 13% of the total 50+ population, see Table 1). For the persons with unmet needs we found 35 thousands with at least one ADL limitation, or 4% of total population 50+. Taking together both groups of persons we arrive to almost 140 thousand persons older than 50 years receiving informal care or have unmet needs.

In the next step we tried to estimate the number of persons who have a chance to enter into the new system of long term care. As regards the entry threshold and ADL limitations, we assumed that we should limit the selection to the group of persons receiving informal care almost every day and having at least one ADL limitation – we arrived to 17,5 thousand persons or to only 17% of all persons with informal home care. For the group with unmet needs we could only assume that we have to seek among all of them. The total number of persons among whom we can find those that would be able to fulfil entry conditions decreased to 53 thousand. But, into which category of CDS scale they belong and how many hours of care per week they need?

Table 1: The estimated number of persons with informal home care or with unmet needs In Slovenia (2013)

	Number	%	Share in population 50+ (%)
TOTAL (informal + unmet needs)	138,973	100	17
UNMET NEEDS	35,307	25	4
INFORMAL HOME CARE	103,666	75	13
TOTAL (informal home care)	103,666	100	13
Receiving care:			
Almost every day	48,802	47	6
- without ADL limitations	31,283	30	4
- with one or more ADL limit.	17,519	17	2
Periodical help	54,864	53	7

Source: data from 5. Wave of SHARE project (Börsch-Supan,2016)

With the use of adjusted CDS scale we estimated categories for both groups (informal home care and unmet need). For the assessment of the reasonableness of the results we assumed that persons, who receive informal home care, are in principle, similar in the care dependency of persons receiving formal home care. The structure of persons as regards the category of CDS care dependency are therefore supposed to be at least similar as better, but expectedly at least slightly better. For persons with unmet needs we would expect even better structure - despite stated ADL limitations these persons succeed to a certain extent to carry out these basic daily activities. The big question is: what is the quality of the activities carried out independently and in general the quality of life of these people. It would be absolutely necessary to carry out a special survey with persons with unmet needs, with the aim of determining the severity of

their situation and the actual needs for care by a third party. In Table 2 and Figure 1 we present the results for the persons who receive formal home care - the average value of the shares from a sample realized in four municipalities (Lekič Polšak et al., 2014) and the results of the assessment of adjusted CDS categorization of persons in informal care and people with unmet needs.

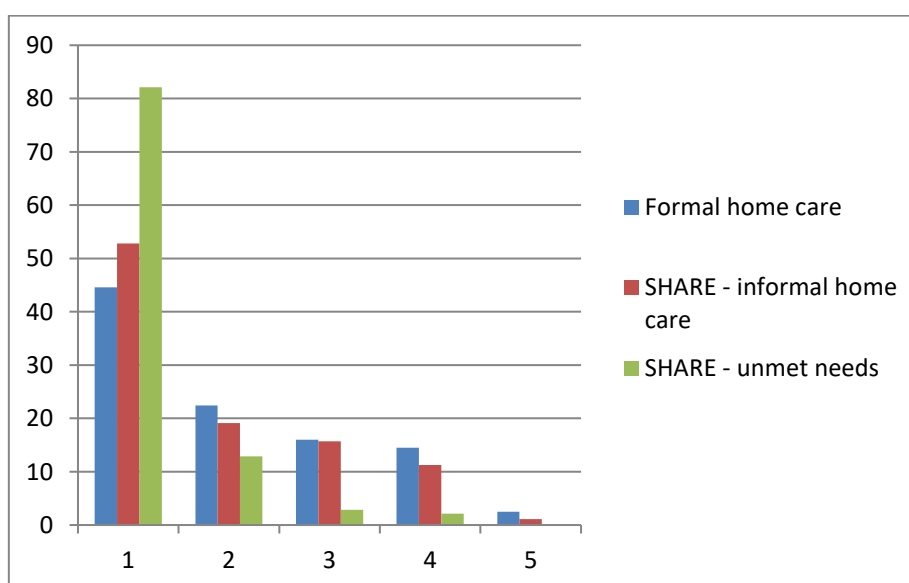
Comparison of the CDS category shares with the ones derived in common classification confirms expectations regarding similar care dependency of persons with informal home care and formal home care. Results obtained for persons with unmet needs reveal much lower care dependency – surprisingly high 82% were classified into the first category, 13% in the second one, 3% in the third and only 2% in fourth category. Low share in the fourth category and absence of persons in the fifth category was expected as persons who are highly dependent on help from third parties would not be able to survive for a longer time without this help.

Table 2: Shares of categories of CDS care dependency

CDS category	Formal home care	SHARE - informal home care	SHARE - unmet needs
Category I	44.6	52.8	82.1
Category II	22.4	19.1	12.9
Category III	16.0	15.7	2.9
Category IV	14.5	11.2	2.1
Category V	2.5	1.1	0.0
TOTAL	100.0	100.0	100.0

Source: survey on formal home care (Lekič Polšak et al, 2014), data from 5. Wave (Börsch-Supan, 2016) and own calculations

Figure 1: Shares of categories of CDS care dependency



Source: survey on formal home care (Lekič Polšak et al, 2014), data from 5. Wave (Börsch-Supan, 2016) and own calculations.

Taking in to account all simplified assumptions and insufficient data on intensity of ADL limitations, first, rough estimate of the number of persons that would be able to enter into the new system of long term care amount to 7.4 – 15 thousand persons (assuming that persons classified into the first category will not be able to enter the system, and that a part or all persons classified into the second category will be able to enter the system). More accurate estimate will be obtained with the use of microsimulation model of the long term care and determination of the entry threshold.

We validated the measured using previously described Heckman's two step selection models. We estimated two equations with basic predictors for both types of equations, closely following the Andersen's behavioral model and elaboration in Srakar et al. (2015). The results are presented below, we test the relationship with Heckman' models and basic probit models.

Table 3 shows the results of modelling using Heckman's two-step correction. We will not go into the interpretation of the coefficients (they are mainly in accordance with the literature, see e.g. Gannon and Davin, 2010; Laferrere and van den Bosch, 2015; Srakar et al., 2015), of our concern is the comparison of the fit of the two models. The disparity is clear. Both information criteria (Akaike and Schwarz) give clear priority to the model, based on the developments of this article (umneed4) and the log likelihood is clearly by far higher for the second model (based on umneed4). This serves as a confirmation that by modelling using the adjusted CDS scale we indeed significantly improved the fit of the model.

Table 3: Results of Heckman's two-step selection modelling

	Regr. equation, umneed5			Select. equation, umneed5			Regr. equation, umneed4			Select. equation, umneed4		
	Coef.	z	P> z	Coef.	z	P> z	Coef.	z	P> z	Coef.	z	P> z
Constant	1.0204	6.35	***	-2.6874	-30.25	***	0.9285	2.65	***	-3.7229	-23.15	***
Gender	-0.1469	-3.88	***	-0.2460	-12.25	***	-0.0653	-0.77		-0.3262	-9.09	***
Age	-0.0244	-13.15	***	0.0091	9.21	***	-0.0276	-7.02	***	0.0084	5.00	***
EduYears				-0.0064	-2.22	**				-0.0067	-1.26	
HhIncome	0.0000	-0.27					0.0000	-0.23				
Settlement	0.0066	0.17		0.0573	2.71	***	0.0124	0.14		0.0679	1.81	*
LivingAlone	0.0526	1.27					0.2374	2.51	**			
ChildDist	0.0014	0.03					-0.0408	-0.45				
FuncLimit				0.3404	84.34	***				0.3687	51.71	***
dwelfreg2	-0.0097	-0.15		0.0979	3.12	***	-0.1084	-0.69		0.1152	1.86	*
dwelfreg3	0.1820	2.35	**	-0.2364	-6.05	***	0.1211	0.63		-0.5067	-6.45	***
dwelfreg4	0.0810	1.17		-0.0695	-1.99	**	0.1150	0.71		-0.0121	-0.18	
dwelfreg5	-0.0122	-0.08		-0.2904	-3.72	***	-0.0742	-0.24		-0.0675	-0.53	
Nr. obs.	56415						56928					
athrho	0.6750						0.2589					
rho	0.5882						0.2533					
LR test idp.eq.	424.96	***					13.83	***				
Log likelihood	-12575						-3738.9					
AIC	25191.1						7521.74					
BIC	25378.9						7718.63					

Source: Own calculations.

This observation is only confirmed when observing the basic probit modelling of the variables umneed4 and umneed5. Again, we will not discuss the signs and sizes of coefficients, but the disparity among the fit of the two models is again wide. Both AIC and BIC are clearly lower for the second model and the log likelihood clearly higher. Although at this point of the article

we do not provide result of the formal testing of statistical significance of this disparity, this verification seems more of a formal nature and clear in the results.

Table 4: Results of basic probit models

	Probit, umneed5			Probit, umneed4		
	Coef.	Z	P> z	Coef.	z	P> z
Constant	-1.5890	-15.38	***	-1.8954	-8.66	***
Gender	-0.2111	-9.21	***	-0.1251	-2.49	**
Age	-0.0047	-4.01	***	-0.0148	-5.96	***
EduYears	-0.0109	-3.30	***	-0.0172	-2.38	**
HhlIncome	0.0000	-0.25		0.0000	-0.19	
Settlement	0.0123	0.51		0.0615	1.16	
LivingAlone	0.0496	1.82	*	0.0425	0.75	
ChildDist	-0.0182	-0.71		-0.1165	-2.16	**
FuncLimit	0.2143	49.31	***	0.2422	28.56	***
dwelfreg2	-0.0358	-1.00		-0.0973	-1.13	
dwelfreg3	-0.1826	-4.17	***	-0.2452	-2.41	**
dwelfreg4	-0.0098	-0.25		0.0386	0.43	
dwelfreg5	-0.3337	-3.66	***	-0.3252	-1.99	**
Nr. obs.	49220			47653		
LR chi2	2749.39	***		1166.88	***	
Pseudo R2	0.1558			0.2834		
Log likelihood	-7446.59			-1475.27		
AIC	14917.18			2976.547		
BIC	15022.82			3090.579		

Source: Own calculations.

Conclusions

Among different activities in the process of preparation of the new long term care system also a triage on a sample of various types of long term care was performed. Based on the data gathered care dependency was estimated, entry threshold determined as well as a set of services that will be provided to the beneficiaries under new legislation. In the next step, generalized estimation of the number of beneficiaries was prepared but its main deficiency was that it did not take into account also possible additional beneficiaries coming from the group of persons with informal care or persons with unmet needs.

Using 5th wave of SHARE data on ADL limitations we were able to prepare estimates of the number of persons 50+ with informal care or with unmet needs. But the data did not provide any information on the intensity of the declared limitations performing of daily living and thus categorization of these persons using the Care Dependency Scale. As the beneficiary must have at least one ADL limitation we decided to develop a limited assessment scale based on all 6 ADL activities and used it for the categorization of persons with informal care or unmet needs. Results obtained were compared with the results from the triage process for formal home care and first, rough, estimate of possible additional beneficiaries was done. Finally, a validation of the measure using econometric modelling was provided confirming a significant advance in the modelling terms when compared to the previous, more general classification.

Work already done on the estimation of the intensity of the ADL limitations is only a first step. Further work based on the existing data is needed as well as search for their possible improvement. There are at least two possible directions. First one refers to SHARE data.

Small change of the question ph049 would certainly improve the quality of information obtained – instead of only two possible answers (YES or NO) we should extend “YES” answer into three answers: a) Yes, and I need help from the third person almost every day, b) Yes, and I need help from third person occasionally, and c) Yes, but I do not need help from the third person. We consider this issue of special importance, as individuals can very quickly state that they have at least some need in ADL or IADL limitations, while they not of the extent to really demand some urgent help, which is also one of the factors driving the results and motivation of this article.

The second one refers to the planned pilot study in the period 2018-2019 whose aim is to evaluate the proposed new long term care system in practice and propose necessary changes. With the extended ph049 question added it would be possible to analyze the results obtained within the triage process (estimated level of care dependency, services and time needed to ensure adequate level of care) and the answers regarding the ADL and IADL limitations.

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