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30 Unmet need for long-term care and social exclusion

- Older people needing long-term care are more likely to suffer from both social and material deprivation than those without such needs
- Older people in countries where the responsibility for long-term care is mainly put upon families are more likely to have unmet needs for care than their counterparts where the government takes on a larger part of the responsibility
- Unmet need is associated with material and social deprivation. At high levels of need, the association is only with social deprivation
- Policy recommendations:
  - expanding systems of formal care may reduce the number of older people with unmet needs for long-term care
  - improving neighbourhood relationships may have the indirect effect of encouraging carers to help with LTC in the community

30.1 Why look at unmet need for long-term care in relation to social exclusion?

While the need for long-term care (LTC) is a significant risk for all ageing populations, LTC provision systems vary across countries within the EU. Where little social protection against long-term care needs is provided, the living conditions of the dependent person and his or her family may be affected (Council of the European Union 2014). Also, older persons may not receive appropriate care.

Earlier studies differ in their estimates of the percentage of people with unmet needs, depending on the type of population analysed and the concept of unmet need used (see García-Gómez et al. 2015 for a review). García-Gómez et al. (2015) found high levels of pro-rich inequity in the use of community care services and in extended home care services in Spain in 2008, while intensive use of informal care services appeared to be disproportionally concentrated on the worse-off. However, apart from a study by Shea et al. (2003) on the USA and Sweden, there appears to be no international comparative research on this issue. Also, to our knowledge there are no previous studies of the relation between deprivation or social exclusion and unmet needs for LTC.

Deprivation and social exclusion can be both a cause and a consequence of unmet needs for long-term care. Persons with few financial and human resources

may find it more difficult to obtain (paid or unpaid) formal care. Small social networks may limit opportunities to receive informal care. Conversely, limitations in daily living activities, especially when no help is provided, may make it difficult to access various services and to take part in social activities. Moreover, bad health and economic conditions in the past could be underlying causes of exclusion and of both need and unmet needs for care in the present. We do not try to unravel those causal paths, but provide an empirical overview of the correlation between exclusion and unmet needs for care. We also look at differences between countries, taking account of differences in LTC systems.

After explaining (section 30.2) how we measure unmet need for care and social exclusion, we first look at the relation between being in need of care and measures of social exclusion (section 30.3). Given that older persons are dependent, we investigate what kind of help they receive in each system of LTC (section 30.4). In section 30.5 we analyse whether unmet need is connected to exclusion, and which particular forms of social exclusion are most important for older persons with unmet needs. Section 30.6 concludes.

30.2 Concepts, data and methods

We consider only those aged 65 and over, who do not live in nursing homes. Limitations requiring care are relatively rare among people aged below 65. Information on care received in nursing homes is insufficient, and the indices of material and social deprivation are less meaningful for people living there. The Czech Republic and Israel are left aside because of a high proportion of missing values on deprivation indices and Luxembourg because of its very small sample size.

30.2.1 Defining needs and unmet needs for long-term care

We define four hierarchical levels of need for long-term care based on the number of lasting limitations in activities of daily living (ADL's), namely dressing, walking across a room, bathing or showering, eating, and getting in or out of bed, and on the number of limitations in instrumental activities (IADL's): preparing a hot meal, shopping for groceries, making telephone calls, taking medications and managing money. Combining the indices for ADL and IADL (from 0 to 3 or more limitations), we get 16 combinations of limitations, from 00 (no limitations), 01 (no ADL, one IADL limitation)... to 32 (3 or more ADL, 2 IADL limitations) and 33 (3 or more ADL and 3 or more IADL limitations).

We define level 1 as having only one IADL limitation (01), level 2 as having one ADL or 2-3 IADL limitations (10, 02 or 03), and level 3 either one ADL and one IADL limitations, or two ADL but no IADL limitations (11 or 20). Finally, level 4 includes all who have more limitations than the previous levels (12, 13, 21, 22, 30, 31, 23, 32, 33).

Overall in our 65+ sample, about one in six (17 %) had a level of need greater than zero, that is needed some form of LTC. Among them, 13 per cent were at the lowest level 1, 39 per cent had moderate needs (level 2), 20 per cent suffered from fairly severe limitations (level 3), while 28 per cent had the highest level of need (level 4).

Facing such needs for care, one can benefit from various types of help. SHARE distinguishes three types: informal help, formal (i.e. professional or paid) personal care and formal domestic help. We assume that ADL limitations require personal care, while for IADL limitations domestic help will be mostly sufficient. We further assume that informal carers provide personal care as well as domestic help, and are able to meet all needs for care, even when no formal care is present. We define a situation of unmet need if either people have one or more IADL limitations and neither formal domestic help nor informal help, or one or more ADL limitations and neither formal personal care nor informal help. This implies that when people have an ADL limitation and only domestic help – but neither formal personal care nor informal care – this counts as unmet need.

This measure of unmet need is an objective one, as limitations and the care received are assessed independently. Objective may be preferable to subjective, self-reported measures of unmet need, which may suffer from self-reporting bias (García-Gómez et al. 2014). However, unlike other objective measures, e.g. those used by Tennstedt et al. (1994), we assess need and care received only in a general sense and not with respect to every type of ADL or IADL limitation separately. Moreover we do not know the number of hours of care or help received. This, together with our assumption that informal care can meet all needs, even in the absence of any formal care, implies that our measure of unmet need should be regarded as indicative only and probably a lower bound on the extent of unmet needs. We use it to discover patterns of unmet need and their correlation with social exclusion.

30.2.2 Measuring social exclusion

Following the definitions from chapter 5 and 6 in this volume, economic or material deprivation is distinguished from social deprivation or exclusion. Material deprivation has to do with the affordability of ordinary consumption goods (gro-

ceries, meat, fruit, clothes, shoes, heating, unpaid rent, mortgage or bills), of health related expenditures (dentist, glasses, doctors) and the inability to cope with extraordinary expenses. Social deprivation or exclusion means being isolated (getting to the nearest bank, doctors or pharmacy is difficult) and living in an unclean, dangerous, non-congenial neighbourhood, where people are unhelpful. We follow the definition of Myck et al. in adding an overcrowded home, low writing or reading skills, low computer skills, and having no local social activity (not attending courses, not taking part in any religious or community organisation). Both indices range from zero to one. Most of those aged 65 and over have some form of social deprivation, while only 49 per cent have a positive value on the economic deprivation index. We also use a binary variable defined as being among the 25 per cent most deprived according to each of the two types of deprivation. According to this criterion, 11.4 per cent of those aged 65 and over are severely deprived.

30.2.3 A LTC welfare state typology

In a recent study, Verbeek-Oudijk et al. (2014) grouped SHARE countries according to their LTC systems. Concentrating on spending on non-residential care, they make a broad division between Northern Europe (Denmark, the Netherlands and Sweden), where the government is mainly responsible for LTC, Central Europe (Austria, Belgium, France and Germany), where responsibility is shared, and countries in Southern and Eastern Europe (Spain, Estonia, Italy, Slovenia and Switzerland), where the family carries the main responsibility for LTC. Interestingly, there is no clear correlation between expenditure on non-residential LTC as a percentage of GDP, and this grouping.

There is no compelling reason to expect that any of these types of LTC system will be associated with more or less unmet need, or with a larger or smaller association of unmet need with social exclusion. Both families and the government can perform their responsibility adequately or can leave gaps.

30.3 Need for care is linked to material and social exclusion

Taking all levels of need together, some 17 per cent of all older persons are in need. The proportion varies from less than ten per cent in Switzerland or the Netherlands to about a one in five in Belgium, Spain, Italy or France and a quarter

Estonia (Figure 30.1). In general, needs are higher in the Southern and Eastern countries than in Scandinavia and Western and Central Europe, even when taking into account that in Sweden, Denmark and The Netherlands, a larger percentage of all 65+ live in nursing homes than in the other countries. Countries also vary in the distribution of levels of need. The severest level of need appears to be relatively common in Italy and Spain.

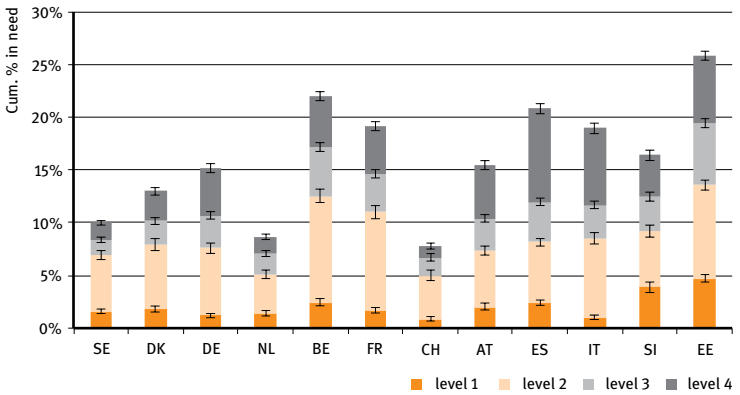

Figure 30.1: Proportion of older persons (65+) in need of care, by country and level of need
Notes: n = 27,799
Source: SHARE Wave 5 release 0

Since LTC needs increase very strongly with age, differences between countries might be affected by the age distributions. However, the same patterns obtain when controlling for the age and gender distribution.

We investigate the association between need for LTC and deprivation by running a number of probit regressions for LTC need, using the levels of need discussed above in a cumulative way. That is, we start with a broad definition of need encompassing all levels, which we subsequently narrow down to the most severe level of need 4. We successively add control variables, starting with demographic variables (age, gender, marital status), continuing with socio-economic variables (education, home ownership, possession of financial assets and/or debts) and finally a range of chronic conditions. We could not use household income because of the large number of missing values; including it for those cases where it was available hardly affected the associations between unmet need and the deprivation variables. Advanced age, renting your home, being less educated, having no financial assets, and suffering from chronic conditions all are associated with LTC need. None of the controls has a substantial effect on the strong association between need for care and social and material deprivation, except for

chronic conditions (results available on request). Inclusion of the latter reduces the association by about 20-25 per cent for material deprivation, and about 16 per cent for social deprivation. A possible interpretation is that bad living conditions in the past are correlated both with the risk of suffering from chronic conditions, and material and social deprivation. Another interpretation is that bad health itself has an impact on social exclusion.

Figure 30.2 shows that need for care and material and social deprivation are strongly associated, even when controlling for a large number of demographic, socio-economic and health characteristics. Being in severe deprivation increases the probability to have any LTC need by about nine percentage points (doubling the probability), and the probability to have needs at the severe level of four by about three percentage points (tripling it). The association is much stronger for social deprivation than for material deprivation, and social deprivation seems to become relatively more important than material deprivation at higher levels of need. One interpretation is that social deprivation, more than material deprivation, is a consequence of the need for care (shops, banks, doctors and the pharmacy became inaccessible when the respondent acquired limitations), in addition to being a cause of need.

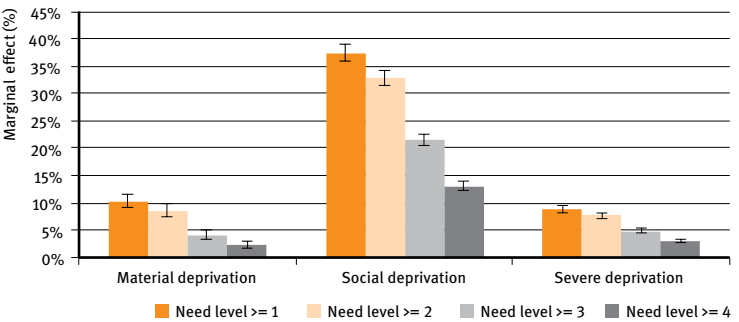

Figure 30.2: Association between deprivation and need for care, controlling for demographic, socio-economic and health characteristics: marginal effects from probit estimates (+ confidence intervals)

Notes: n = 24,683; material and social deprivation were entered in the same model; severe deprivation was entered in a separate model (to avoid artificial collinearity, as the latter is based on the former)

Source: SHARE Wave 5 release 0

30.4 A third of older persons in need did not receive adequate care

What kind of care do older people with limitations receive? We distinguish between informal care, formal personal care and formal domestic help and we use the definitions of unmet need (i.e. no appropriate care) discussed in section 30.2.

Figure 30.3 shows, unsurprisingly, that people are more likely to receive care the higher their needs. The biggest divide lies between need level 2 (only one ADL limitation and no IADL limitation, or no ADL limitation and one or several IADL limitations) and need level 3 (two ADL limitations, or one ADL and one IADL limitation). Also interesting are the differences between LTC systems. At all levels of need, persons in countries where the government takes the main responsibility for long-term care ('Type 1 state-LTC') are more likely to receive formal care than in countries where responsibility is shared between government and families ('Type 2 shared-LTC'), and even more than in countries where responsibility is mainly put upon families ('Type 3 family-LTC'). In the latter countries, families generally do not shirk this responsibility, as shown by the much larger proportions of older persons getting (only) informal care. Nevertheless, ultimately the proportion of older persons left with unmet needs is also higher in the family-LTC countries,

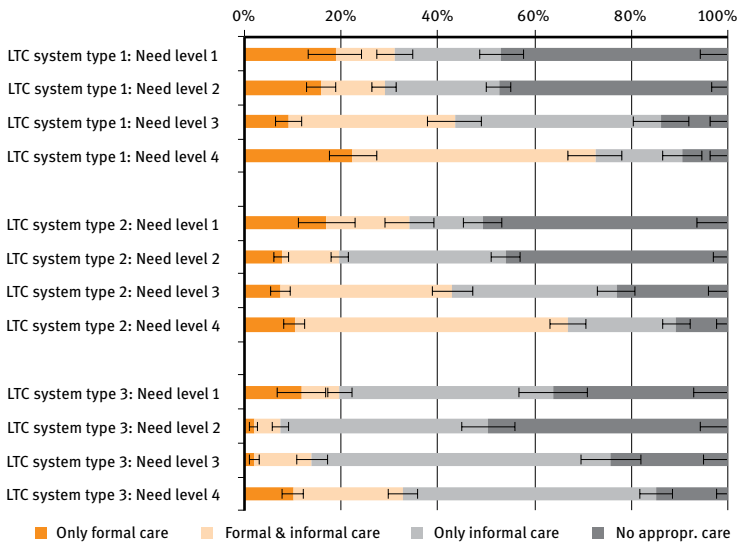

Figure 30.3: Kind of care received by older people in need of care, by level of need and LTC system type
Notes: n = 4,714
Source: SHARE Wave 5 release 0

compared to the shared-LTC and state-LTC countries, especially at more severe levels of need (these differences between LTC-types are statistically significant). Overall among the 65+ a third did not receive adequate care or help. While the prevalence of unmet need falls with the level of need, it was still around 15 per cent at severe need levels.

30.5 Unmet need for care, exclusion and the welfare state

Obviously one can only have unmet need if one is in need of long-term care. For the analysis of the association between unmet need and social and material deprivation this creates what is called in econometric terms a possible "selection bias". For this reason we used Heckman probit regressions to analyse this association. As shown in section 30.3, the "selection" into LTC need is mainly a function of age, gender, country, deprivation and health conditions. Given that a person is in need of care, we assume in a second step that experiencing unmet need depends on the number of ADL and IADL limitations, education, home ownership, possession of financial assets and debt, country, living in a couple and gender, as well as of course social and material deprivation.

Such models, while still descriptive, partly control for contemporaneous factors affecting both needs and the way they are met. The results, shown in Figure 30.4, show that material and social deprivation levels are related to a higher probability of having unmet needs at the lowest levels of needs. At levels of need above 3, only social deprivation matters. As for the severe deprivation index, it is correlated to unmet needs at all levels, except for people with the highest level 4.

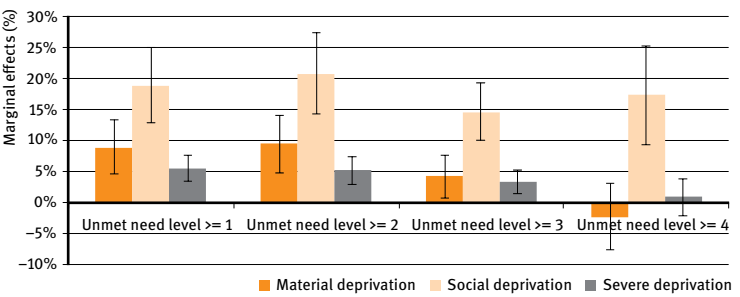

Figure 30.4: Association of social, material and severe deprivation with unmet need for care at four progressively higher levels of need, marginal effects from probit estimates
Notes: n = 24,683
Source: SHARE Wave 5 release 0

Looking at the association of unmet need and severe deprivation separately for the three groups of welfare state regimes (Table 30.1), we find that the probability to have *unmet* needs is somewhat higher under the Central system than the Nordic system, and higher under the South-East system than under the Central system. The association with severe deprivation, everywhere positive, does not

Table 30.1: Association of severe deprivation and unmet need for LTC, at four progressive need levels and within three LTC systems, probit coefficients

	Unmet need level >= 1		**Unmet need level >= 2**		**Unmet need level >= 3**		**Unmet need level >= 4**	
VARIABLES	Coeff.	St. error	Coeff.	St. error	Coeff.	St. error	Coeff.	St. error
Severe deprivation	0.118*	0.067	0.082	.073	0.110	0.101	0.020	0.140
Northern (state LTC)	ref	ref	ref		–		–	
Central (shared LTC)	0.078	0.067	0.117§§	0.074	0.121	0.101	0.022	0.146
South-East (family LTC)	0.197***	0.075	0.212***	0.082	ref		ref	
Severe deprivation # South-East (family LTC)	ref	ref	ref	ref		ref	ref	ref
Severe deprivation # Northern (state LTC)	–0.150	0.246	0.119	0.251	–		–	
Severe deprivation # Central (shared LTC)	0.178§§	0.113	0.232*	0.121	0.252§§	0.162	0.176	0.233
Observations	24,683		24,683		19,105		19,105	

Robust standard errors in parentheses, *** p<0.01, ** p<0.05, * p<0.1, §§ p<0.15
Note: Estimated coefficients from 4 Heckman selection probit models: 4 progressive levels of need with interaction terms of severe deprivation with welfare regimes. The Nordic countries are excluded from the level 3 and 4 models with interactions. All models include ADL and IADL levels, demographic and socio economic variables. See text of section 30.3 for the selection models (probability to have LTC need).
Source: SHARE Wave 5 release 0

differ much across welfare regimes. At fairly low level and intermediate levels of disability, it seems more positive in the Central countries. Severe deprivation is more strongly associated with unmet needs in Central Europe than in the Southern and Eastern countries (the effect is not significant for the highest levels of need; the Nordic countries are excluded for unmet need at level 3 or more because unmet need at those levels of need is very rare there). A tentative interpretation could be that for those severely deprived the family is essential in complementing the welfare state, and family is more efficient and present in Southern and Eastern countries than in Central Europe.

What type of social deprivation is related to unmet needs for care? In a final analysis seven of the more relevant elements of the index of the social deprivation are introduced separately (difficulties in getting to the nearest bank, doctors, pharmacy, living in unclean, dangerous, uncongenial neighbourhood, where people are unhelpful). We also add variables indicating the degree of urbanisation of the place of residence, from big city to rural areas, with the idea that some people might have more unmet needs because they live far away from care providers. Living in an area where people are perceived to be unhelpful is found to be the only element linked to unmet need for care. Perhaps surprisingly, living in a big city is also detrimental, though only at low needs for care. A possible policy implication is that improving neighbourhood relationships may have the indirect effect of encouraging carers to help with LTC in the community.

30.6 The more deprived, the more need for long-term care, and the more often these needs remain unmet

We distinguish four levels of LTC need, based on the combination of ADL and IADL limitations. Needs for LTC were higher in the Southern and Eastern countries than in Scandinavia and Western and Central Europe. Deprivation was clearly linked to LTC needs, even when controlling for demographic variables, socio-economic position and chronic conditions. There seems to be a direct link, although we cannot unravel its causal direction.

Relying on data on care and help received we estimated that among those needing LTC, a third did not receive adequate care or help. While the prevalence of unmet need falls with the level of need, it was still around 15 per cent at severe need levels. Unmet needs were found in all countries, though in the majority of cases at lesser levels of need. In the South and East of Europe, where the respon-

sibility for long-term care is mainly borne by families, a substantial proportion of older persons had to cope with fairly severe needs which are unmet neither by formal nor by informal care or help. The proportion was smaller in countries where the state takes on most of this responsibility (Sweden, Denmark, the Netherlands). Countries where the responsibility is shared between the state and families were intermediate.

Not receiving appropriate care was linked to deprivation. It is as if those in deprivation faced a double penalty: more likely to have limitations, and at the same time less likely to receive help. But we found some sign that severe deprivation is less problematic in the South and East than in Central Europe, probably because of the strong role of the family.

We also found, surprisingly, that older people living in big cities more often have to cope with unmet LTC needs. Among other reasons, it is probably the quality of the neighbourhood that is a problem. More work is clearly needed to untangle the various effects.

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