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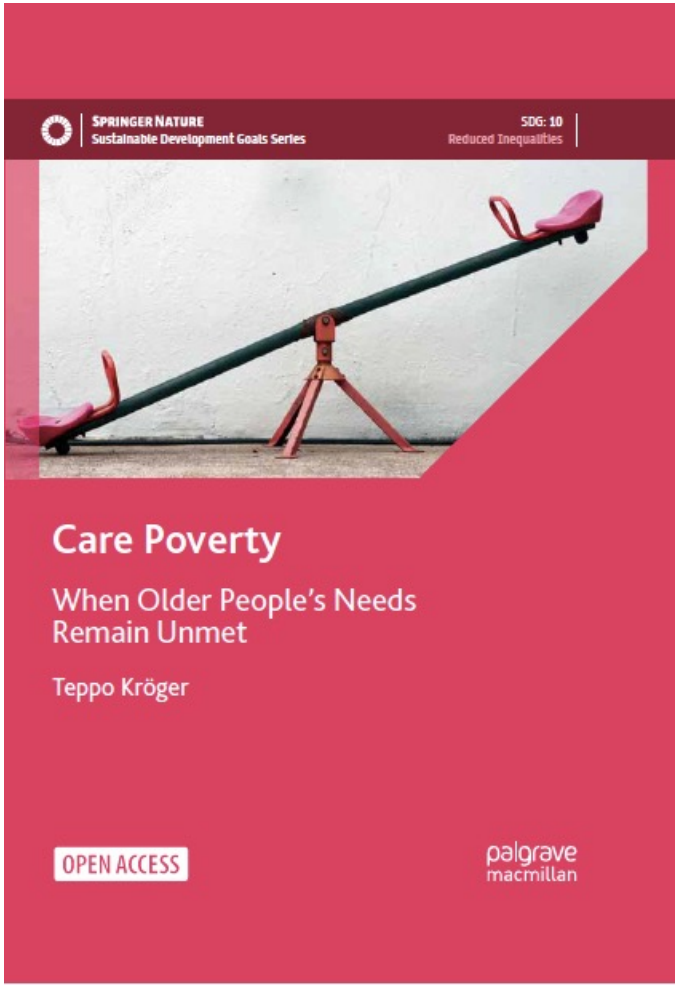
Care Poverty: When older people's care needs remain unmet

Teppo Kröger

CoE AgeCare/University of Jyväskylä

The Open Access book (2022)



The need for a new approach

- Research on social care has focused on indicators like
  - Expenditures (% of GDP)
  - Volumes of service provision (% of age groups)
- And (in social policy) on concepts like
  - Marketisation
  - Familialism or De-/Re-familisation
  - Personalisation
- While these are certainly useful, they do not provide an answer to the primary (outcome) question:
  - *Do people who need help receive adequate support?*

Unmet needs

- In gerontology, the concept of *unmet (long-term care) need(s)* has been used since the 1970s
- It is a parallel concept to unmet health care need(s) that is measured, e.g. by waiting times to medical care
- Williams et al. (1997): “Unmet need occurs in long-term care when a person has disabilities for which help is needed, but is unavailable or insufficient”.
- Especially since the 1990s, a rapidly growing literature on unmet needs has emerged, especially in the US
- In the 2000s and 2010s, studies on unmet needs have increased also in Europe (especially in the UK and Spain), Asia and even Africa

Unmet needs

- Methodological issues
  - Unmet needs are measured in several different ways, which makes it difficult to get a general view of their incidence even in one country, not to mention between countries or of changes in time
  - Unmet needs are often measured as total absence of all formal and informal care, which leads to a serious underestimation of the problem
  - Especially: lack of reliable international longitudinal datasets on the issue

Unmet needs

- Conceptual issues
  - Unmet needs is often used as a pseudo-medical term (e.g., speaking about prevalence) but lacking adequate care is not an illness, it is a social phenomenon/problem
  - The term of unmet needs lacks a theoretical foundation. In particular, it is separate from social research discussions on inequality, deprivation, disadvantage and social exclusion, and from human rights discussions, as well

Care poverty

- Care poverty means a situation where, as a result of both individual and structural issues, people in need of care do not receive sufficient assistance from informal or formal sources, and thus have care needs that remain uncovered.

Care poverty

- The concept of care poverty aims to build a new starting point for discussion on unmet care needs
- It connects (gerontological) studies on unmet needs to social policy literature on care systems and, furthermore, to research on poverty and social inequality
- Following the thinking of poverty research, care poverty is seen as *a lack of resources*, that is, as a lack of informal and formal care resources

Care poverty

- Lack of adequate care (just like poverty) is not only a question about individuals and their capacities, it is also about social structures
- The distribution of (care) resources among the (older) population in a society is a societal, political and social policy issue
- Care poverty – if it exists – can thus be understood as *a failure of the welfare state* (in particular, a failure of its care policies)
- It can also be seen as *a deprivation of a basic human need* and, thus, as *a human right violation*

Care poverty

- Care poverty is not a subcategory of poverty but rather its parallel concept:
  - poverty is about a lack of material resources
  - care poverty is about a lack of (immaterial) care resources
- Empirical studies show that poverty and care poverty/unmet needs are usually connected (as material resources can often be exchanged to care resources) but these two are still separate phenomena

Care poverty

- A review of existing studies on unmet needs shows that, besides low incomes, care poverty is connected to living alone, poor health and a high number of I/ADL limitations
- Several factors thus affect care poverty, but this does not mean that care poverty can be reduced back to them. Whether or not care needs are met is *a social issue in its own right*.

Care poverty

- Poverty rate (OECD 2021):

  the ratio of people in a given age group whose income falls below the poverty line

- *Care poverty rate*:

  the ratio of people, in a given group of people with care needs, whose care needs are not met

Care poverty framework

- In order to be able to summarise the existing literature on unmet needs, the book introduces a new framework
- This framework is based on two issues
  - Domains of care poverty

    (based on different categories of care needs)
  - Measurement of care poverty

    (based on different methodologies)

Domains of care poverty

- Personal care poverty
  - Lack of support for personal care needs (ADLs)
- Practical care poverty
  - Lack of support for practical care needs (IADLs)
- Socio-emotional care poverty
  - Lack of support for social and emotional needs
  - Resulting, for example, in loneliness

Measurement of care poverty

- Absolute care poverty
  - Having care needs but receiving no informal or formal care at all
- Relative care poverty
  - Having care needs but self-reporting (or being reported by a proxy respondent) of not receiving adequate support
  - May receive some informal or formal support but this is not enough/adequate to satisfy care needs
  - Not relative to the general level of unmet needs within the whole population (as that does not make sense for care needs) but relative to general expectations and norms concerning adequate care in each society

Care poverty framework

Care poverty domain	Care poverty measurement	
	Absolute care poverty	Relative care poverty
Personal care poverty	Absolute personal care poverty	Relative personal care poverty
Practical care poverty	Absolute practical care poverty	Relative practical care poverty
Socio-emotional care poverty	Absolute socio-emotional care poverty	Relative socio-emotional care poverty

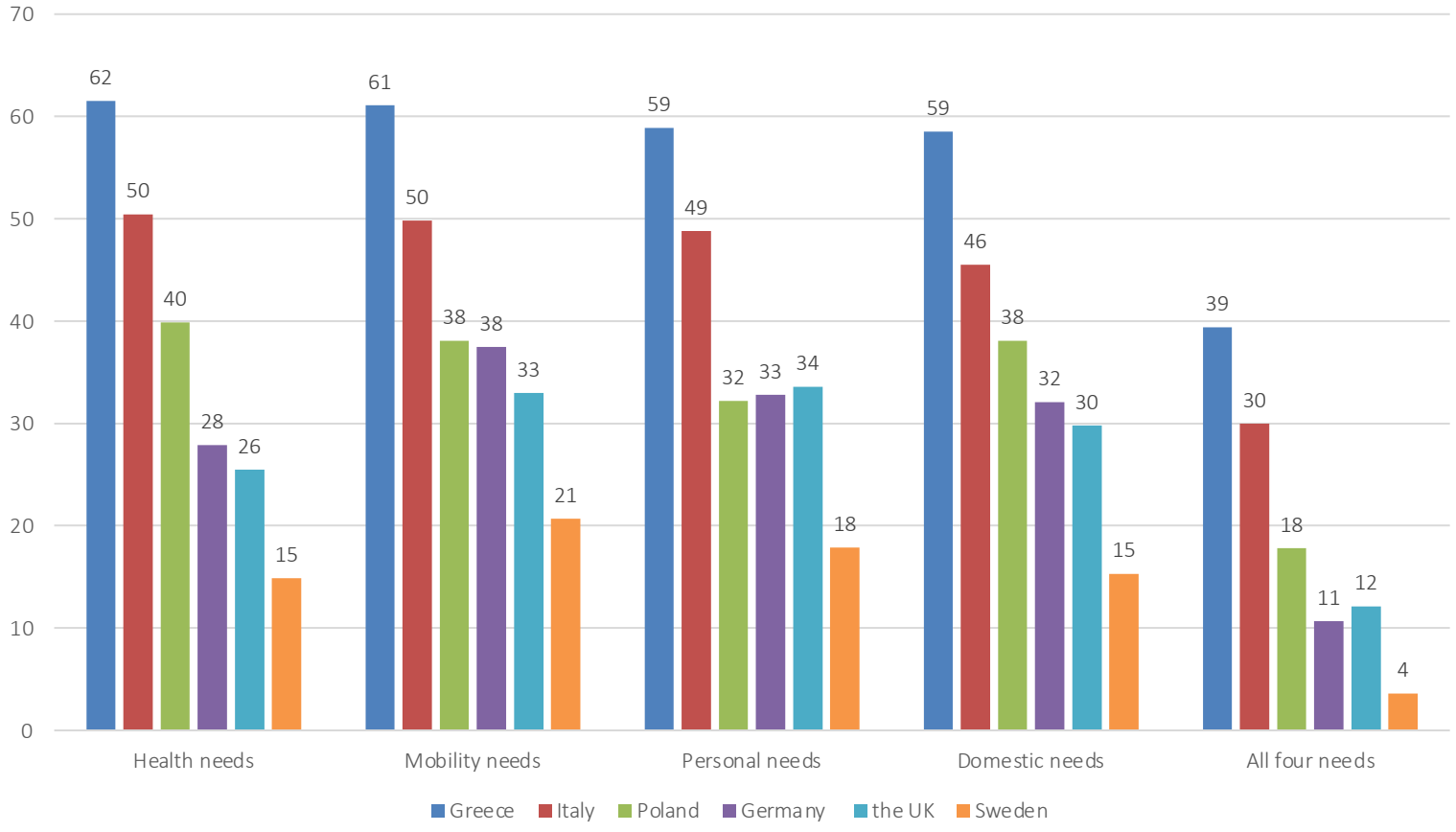
Absolute personal care poverty rates

Table 4.1 Rates of absolute personal care poverty

Country	Study	Age group	Sample size	Data from year(s)	Care poverty rate (%, rounded)
US	Manton (1989)	65+	3499	1984	35
US	Tennstedt et al. (1994)	70+	235	1984	9[a]
US	Sands et al. (2006)	70+	2943	1992–1997	18
US	Davey et al. (2013)	65+	2422	2004	41
US	Freedman and Spillman (2014)	65+	8077	2011	27/48[a,b]
Spain	Tomás Aznar et al. (2002)	75+	351	1998	22
Canada	Carrière (2006)	65+	28,672	2003	42[c]
UK	Vlachantoni et al. (2011)	65+	3356	2001–2002	52[a,c,d]
		65+	4916	2008	50[a,c,e]
UK	Whalley (2012)	65+	4231	2011–2012	76[a,c]
UK	Maplethorpe et al. (2015)	65+	2067	2014	87[a]
UK	Dunatchik et al. (2016)	65+	2090	2012–2013	70[c]
UK	Marcheselli and Ridout (2019)	65+	2253	2018	87[a]
UK	Vlachantoni (2019)	65+	5591	2014–2015	55
Malaysia	Momtaz et al. (2012)	60+	400	2003–2005	14[c]
NZ	Wilkinson-Meyers et al. (2014)	75+[f]	3753	2008–2009	7
China	Zhu and Österle (2017)	45+[g]	3682	2013	31[a]

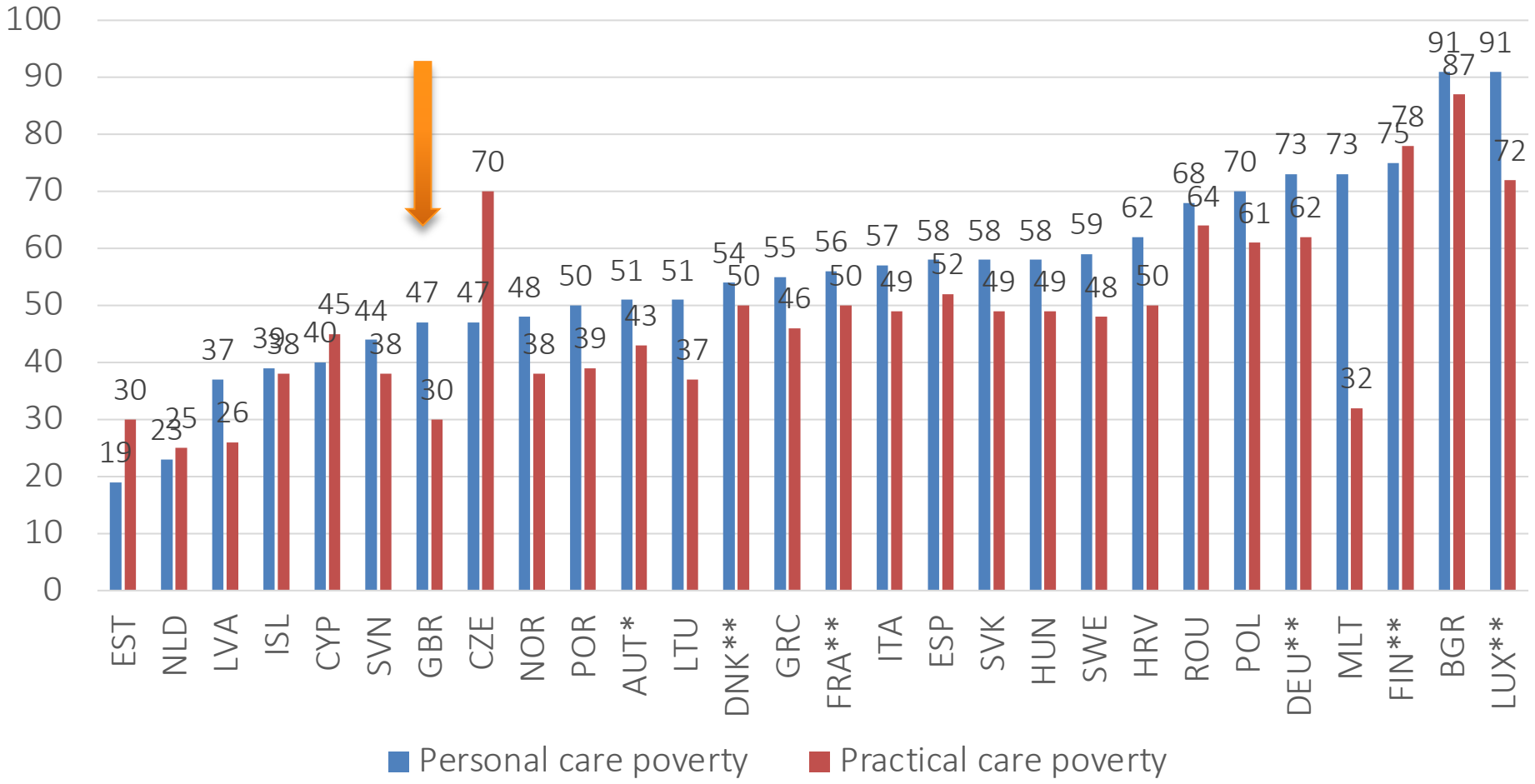
[a]Recounted based on information provided in publication
[b]Depending on whether or not the category of 'has some limitations but does not experience difficulty or receive help' is interpreted as having care needs
[c]As the publication reports only activity-specific rates, the table shows the highest activity-specific level of unmet needs (for Dunatchik et al., 2016, the figure is based on levels reported in the Appendix, Table A2)
[d]Based on GHS dataset
[e]Based on ELSA dataset
[f]65+ for Māori participants
[g]The publication reports results only for the whole sample, but the majority (54%) of the sample was aged 65+

Comparative unmet need studies



(EUROFAMCARE project data 2003/2004)

Comparative unmet need studies



(EHIS data 2014:
*/** Low reliability)

Factors of care poverty

	Health and functional status		Socio-demographic factors								Availability of informal and formal care				
	Health (poorer)	I/ADL limitations (more)	Age (older)	Gender (female)	Marital status (not married)	Ethnicity (minority)	Income (lower)	Education (lower)	Home ownership (rented)	Residential area (rural)	Living arrangement (alone)	Informal networks (weaker)	Primary source of care (informal)	Region	Access to formal care (no)
5.1 Absolute personal care poverty	SIG/ NS	SIG	NS	SIG/ NS	SIG/ NS	SIG/ NS	NS	NS	SIG/ NS	NS	SIG	NS	NS		SIG
5.2 Relative personal care poverty	SIG	SIG	NS	NS	NS	NS	SIG	NS	NS	SIG	SIG	SIG/ NS	SIG/ NS	SIG /NS	SIG/ NS
5.3 Practical care poverty	SIG	SIG	SIG /NS	NS	SIG/ NS	NS	SIG	NS	NS	NS	SIG/ NS	SIG/ NS	SIG/ NS	NS	
5.4 Absolute personal-practical care poverty	SIG	SIG	SIG /NS	NS	SIG	SIG/ NS	NS	NS	NS	SIG/ NS	SIG	SIG		SIG /NS	SIG/ NS
5.5 Relative personal-practical care poverty	SIG	SIG	SIG	SIG	SIG/ NS	SIG/ NS	SIG	NS	NS	SIG	SIG	SIG/ NS	SIG	SIG	SIG/ NS
5.6 Socio-emotional care poverty	SIG	SIG	SIG /NS	SIG/ NS	SIG		SIG	SIG/ NS			SIG				
Total	SIG	SIG	SIG /NS	NS	SIG/ NS	NS	SIG	NS	NS	SIG/ NS	SIG	SIG/ NS	SIG/ NS	SIG /NS	SIG/ NS

SIG: Most studies show significant association. SIG/NS: Around half of the studies show a significant association.
NS: Most studies show no significant association.

Consequences of care poverty

	Adverse consequences	Cognitive decline	Physical health problems	Depression	Emotional well-being	Mortality	Use of health care	Use of residential care
Personal care poverty	SIG			SIG		SIG/ NS	SIG	SIG
Practical care poverty	(SIG)			SIG/ NS			(NS)	
Personal-practical care poverty	SIG			(SIG/ NS)	SIG		SIG	
Socio-emotional care poverty		SIG	SIG	SIG	SIG	SIG	SIG	(SIG)
Total	SIG	SIG	SIG	SIG/ NS	SIG	SIG/ NS	SIG/ NS	SIG

SIG: Most studies show a significant association.
SIG/NS: Around half of the studies a show significant association.
NS: Most studies show no significant association.
( ) This issue is reported by only one study reviewed here.

Adverse consequences of personal care poverty

Country	Study	Age group	Wetting/soiling oneself	Unable to use bathroom	Unable to bathe	Unable to get dressed	Went hungry	Went without clean clothes	Unable to get out of bed	Falls	Unable to move inside
US	Allen and Mor 1997[1]	65+	33	21	29		5	7		22	5
US	Desai et al. 2001[2]	70+		51	42	20	21				40
US	LaPlante et al. 2004[2]	18+[3]	30	27	35	20	15	16	23	55	52
US	Komisar et al. 2005[2,4]	67+	56/ 15		42/ 33	23/ 14	18/3			48/ 28	
US	Allen et al. 2014[1]	65+	43		13	8	4		12		26
US	Freedman and Spillman 2014[1]	65+	43		13	8	4		12		26
US	Beach et al. 2020[1]	65+	8		4	3	1		5		10

[1] Share (%) of people with adverse consequence among those with care needs.
[2] Share (%) of people with adverse consequence among those with unmet care needs.

Care poverty and social inequalities

- A low *income level* is a risk factor for personal care poverty in some but not in all countries, while it is more systematically associated with practical care poverty and socio-emotional care poverty.
- A low level of *education* does not typically predict care poverty.
- Neither does *gender*, though at the same time the clear majority of older people in care poverty are women.
- Some studies identify an *ethnic or racial gradient* in care poverty, minorities being more likely to have unmet needs. At the same time, several studies fail to show statistical significance for this difference.

Care poverty and social inequalities

- Concerning *regional inequalities*, there are major differences in care poverty rates across different areas, at least in geographically large countries, and in some cases also between rural and urban areas (though sometimes it is rural, sometimes urban areas with more care poverty)
- Social inequalities have also an impact on the consequences of care poverty
- When some people receive adequate care while others do not, a new type of inequality emerges. That is why care poverty is to be understood as *a dimension of social inequality on its own*.

Care poverty and care systems

- Comparative evidence on care poverty is still very weak as reliable international datasets simply do not exist
- The few Europe-wide studies suggest high rates of care poverty especially in Eastern and Southern European countries
- A handful of two-country studies exist and they support the importance of formal home care in reducing care poverty, echoed in local and national studies
- *Well-coordinated and well-resourced universal formal care systems* (e.g. Sweden) seem to be the most effective way to eradicate care poverty

Care poverty and LTC systems

- At the same time, American studies show that Medicaid has in the US played a major role in cutting down care poverty, being targeted at low-income older people who are at the highest risk
- In the absence of a universal care system, *a targeted system* can thus be a good second choice: it will not fully eradicate care poverty, but it can still succeed at substantially alleviating it

Conclusions

- Research on care systems has largely focused on used resources (% of GDP) and volumes of provided services
- However, neither of these tell anything about the outcomes of social care
- The main objective of care services for older people is to satisfy care needs of the older population
- That is why it is necessary for research as well as policy and practice to start to direct its attention to whether this objective is reached or not

Conclusions

- *Care poverty* is a new concept that utilizes the older term of *unmet long-term care needs* but extends it towards social policy and poverty research
- Care poverty with its three domains can be understood as a critical indicator that measures the outcomes of care policies and welfare systems
- Being left without adequate care signals a major social inequality and a breach of human rights

Conclusions

- Unfortunately, care poverty seems to exist and be rather widespread across the world
- More knowledge is needed in order to understand the phenomenon of care poverty in depth and to plan new policies and practices that could lead to its eradication – or at least: major alleviation