# Introduction: Unmet care needs and care poverty in international perspective

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## Introduction

The ongoing rapid population ageing and the resulting increase in care needs has made securing the provision of care a burning policy question around the world. Populations are ageing practically everywhere, in the Global South as well as in the Global North, in the East as well as in the West. Along with climate change, demographic change is increasingly recognised as a grand societal challenge that, if not adequately addressed, can threaten not only the quality of life and human dignity of older people, but also the labour market participation of their family members, the balance of national economies and even the legitimacy of political decision-making. As a sign of awakening to these threats, the European Union launched in 2022 its European Care Strategy, stressing the need for Member States to provide affordable and adequate access to high-quality long-term care services for all those in need (European Union, 2022). The fact that such a high-level policy announcement was deemed necessary implies that the reality across Europe is far from this goal, that in practice care services are often of low quality, unaffordable and inadequate, and that many people in need do not have access to them – and that informal care can no longer solve the situation. And on a global scale, Europe is certainly not in the weakest position to meet the growing care needs of older people.

This bleak situation is the starting point for this book. We know from previous research that in every country there seem to be at least some older people who do not get the help and support that they need, either from the state or from their families and social networks. Their care needs are not being adequately covered, so they have 'unmet needs'. This term is most commonly used in North American gerontology, where a specific stream of research developed in the 1990s to measure and examine the incidence of such situations and their determinants and consequences (for example, Allen, 1994; Tennstedt et al, 1994; Allen and Mor, 1997; see also Kröger, 2022). In the early 21st century, this research has also developed in Europe and other parts of the world (for example, Tomás Aznar et al, 2002; Gureje et al, 2006; Vlachantoni et al, 2011; Peng et al, 2015).

Recently, research on the unmet long-term care needs of the older population has grown in several countries. Knowledge of the problem and its occurrence has increased and new methods of analysis have been developed. However, this progress is overshadowed by the fact that this research has mainly focused on the individual level of older people and has mostly been carried out in isolation from social policy research. As a result, its contribution to highlighting the inadequacies of current policies and the way forward in developing more appropriate policy models has remained limited.

In order to establish a closer link between research on unmet needs and social policy, and social science more generally, a new conceptual framework has recently been proposed. The concept of 'care poverty' highlights the structural and policy contexts of the phenomenon of unmet needs and emphasises the need to understand deprivation of adequate care in the same way as deprivation of material resources, that is, as a social inequality rooted in how resources are distributed between different population groups in society (Kröger et al, 2019; Kröger, 2022). According to this approach, only by addressing these structural issues is it possible to find effective strategies to address the unmet needs that older people experience in their daily lives.

This book aims to promote research on unmet care needs, particularly through international collaboration, which has been limited to date. Research on this topic has more than academic value. Without knowing which groups of older and disabled people are particularly at risk of going without the support they need, which of their needs are most often unmet, and what the negative consequences of such a situation are for their health and quality of life, it is difficult, if not impossible, to develop policies that could eradicate the problem. At the same time, by introducing the conceptual approach of care poverty and its potential contributions to research and policy, this volume aims to go beyond previous literature on unmet needs. Solving a social problem requires a comprehensive understanding of its scope, causes and mechanisms, as well as the impact that different policy interventions may have on it. Such an understanding requires a more expansive perspective than that offered by the concept of unmet need, and the new care poverty approach, which brings together gerontology, social policy and poverty research, can contribute to such a broader perspective.

## The concepts of unmet needs and care poverty

As already mentioned, the concept most commonly used in research on the lack of adequate care and support for disabled and older people is that

of unmet need. There are several different definitions of this concept. For example, Williams et al (1997: 102) state that '[u]nmet need occurs in long-term care when a person has disabilities for which help is needed, but is unavailable or insufficient'. Typically, unmet need is measured using lists of Activities of Daily Living and sometimes Instrumental Activities of Daily Living, looking at whether there is a gap between help needed and help available in one or more of these activities (for example, Allen and Mor, 1997). Most studies of unmet needs are based on questionnaire surveys in which either disabled/older people or their family members or care professionals have reported their needs and whether or not these are being met.

Compared to the concept of unmet need, the concept of care poverty is more recent. It has been developed to build links between studies of unmet needs and social policy research, particularly feminist care policy research (Kröger, 2022). Care poverty has been defined as 'inadequate coverage of care needs resulting from an interplay between individual and societal factors' (Kröger et al, 2019: 485). It highlights the structural background of unmet care needs and shifts attention from the individual level to the societal level, emphasising how the problems of disabled and older people and their carers are embedded in structural contexts. Care poverty is not seen as part of material poverty, but as a parallel concept: poverty is about deprivation of material resources, while care poverty is about deprivation of informal and formal care resources (Kröger, 2022). Both are expressions of social inequality between those who have sufficient resources and those who do not. By making the conceptual link between lack of adequate care and poverty, the aim is to learn from the rich conceptual and methodological toolkit of poverty research and, where possible, apply it to care research.

### Aims of the book

This book suggests a change of perspective for international research on care for older and disabled people. Up to now, research has largely focused on inputs – in particular care expenditures – and outputs – that is, the volume of services provided. Knowledge of these is undoubtedly useful, but care policies need to be evaluated primarily in terms of their main objectives. The key objective of long-term care systems is to meet the support and care needs of the older and disabled population, as well as informal carers, and whether or not this is happening deserves to be the main focus of the evaluation. In addition to inputs and outputs, more attention needs to be paid to outcomes. Are some policies more effective than others in reducing unmet needs? Are there differences between countries and their long-term care systems in their ability to meet care needs and eliminate care poverty? What is the role of informal versus formal care in ensuring access to adequate support? How can the perspectives and experiences of people in need of care be taken into account when examining these issues?

The aim of this volume is to advance this discussion at the international level. As noted earlier, there is a gradually growing literature at the national and local level in several countries examining the unmet care needs of older people, but there has been little international discussion or research on this issue and no collective attempt to consolidate empirical evidence, theories and concepts on the issue in a coherent way within a common framework.

Based on a collaboration of social policy researchers from a number of countries and welfare settings, this book reviews and synthesises the state of the art of research on unmet care needs of older and disabled people. It brings together not only the empirical evidence but also the theoretical and methodological approaches of this emerging strand of research literature. This empirical, theoretical and methodological knowledge is then framed and discussed under a new concept, that of care poverty, and its relevance and potential for research on the lack of adequate care in different social and cultural contexts is explored. The book thus develops the theoretical and methodological foundations of this rapidly expanding area of social policy analysis.

The book also presents new empirical evidence on how care poverty is distributed across different groups from a range of welfare states in and outside Europe. These studies strengthen the knowledge base on which the value of different policy approaches and practices can be discussed. In doing so, the book updates and extends the review of previous literature on unmet care needs. This book represents a collective international effort to outline the way forward for research on unmet needs and care poverty.

## Background of the book

The book is based on an international research network. In January 2020, the Care Policy Evaluation Centre of the London School of Economics and Political Science and the Centre of Excellence in Research on Ageing and Care from Finland co-organised a workshop in London where around 25 care policy researchers from over ten different countries shared their research on unmet long-term care needs of older and/or disabled people. During the workshop, the participants formed a new international research network called 'Unmet Needs, Inequalities and Care Poverty' (UNICAP). The network aims to promote research on the inadequate provision and receipt of care and support for older and disabled people through international collaborative research, joint publications and research events focusing on the issue.

This book is a product of collaboration within the UNICAP network. Its authors are experienced researchers from 11 different countries (Australia,

Austria, Canada, Denmark, Finland, Germany, Hungary, Portugal, Slovenia, Sweden, United Kingdom). Most of them are from Europe, representing its different welfare models: Nordic, Bismarckian, British, Central and Southern European systems, plus Australia and Canada. The chapters reflect the policy traditions and research approaches in these countries, while all addressing unmet needs and care poverty and contributing to the overall aim of the book to analyse care inequalities from an international perspective. Draft chapters were discussed and developed in two author workshops, one online in March 2023 and the other held in conjunction with the Transforming Care 2023 conference in Sheffield in June 2023.

## Structure of the book

In addition to and between this introductory chapter (Part I) and the concluding chapter (Part IV), the book is divided into two main parts, one focusing more on theoretical and methodological issues (Part II) and the other presenting new empirical analyses of care poverty and unmet needs from different national contexts (Part III).

Part II includes chapters that develop new conceptual and measurement approaches to the study of unmet needs and care poverty. It begins with two chapters that assess the theoretical value of the concept of care poverty and link it to other ongoing conceptual debates. First, in Chapter 2, Rummery situates the care poverty approach in the context of other care theories and reviews the conflicts inherent in these theories. She connects care poverty to social citizenship – to the right to access resources to meet needs, in this case care needs. The chapter applies ideas about care poverty to offer a theoretical way of synthesising previous conflicting theories of care, and uses this synthesis as a lens through which to understand gendered citizenship.

In Chapter 3, Kelly also discusses the theoretical value of the care poverty approach. In particular, she links care poverty to the concept of the care economy, which positions care as a mode of production with tangible implications for other sectors of the economy and for those who participate (or not) in the care workforce. Using Canada as a case example, the chapter shows how a care poverty framework moves the concept of unmet needs from documentation and measurement towards solutions and policy change. It concludes that care poverty is a more complete accounting of unmet care needs in context, an indicator of a malfunctioning care economy, and a reminder that transformative change can occur through the way societies organise care.

These two theoretical chapters are followed by two methodological chapters. In Chapter 4, Hill et al review 29 different measures of unmet need drawn from the disciplines of health, gerontology, social sciences and human rights, and propose a holistic approach to measuring unmet care needs

of older people. Using Australia as an example, the chapter highlights the role that measurement can play in transforming a system based on rationing substandard care into one that enforces a universal right to quality care based on assessed need.

Furthermore, in Chapter 5, the final chapter of Part II, Medgyesi et al start to develop methods for measuring care poverty. Building on existing approaches to (income) poverty measurement, they discuss the advantages and disadvantages of different ways of assessing unmet needs and care inequalities, and how poverty measurements could be adapted to quantify care poverty. They place a particular emphasis on different approaches to comparative research.

Part III of the book contains chapters that empirically analyse care poverty and unmet needs in a range of different societal and cultural contexts, each bringing a unique perspective and broadening the understanding of care poverty. These chapters open up new ways of analysing unmet needs and related phenomena and move the field forward, taking into account national contexts. An important contribution is to show that care poverty affects not only older and disabled people but also their family members, in particular their informal carers. Unmet needs of older or disabled family members can become transformed to unmet needs of carers if adequate support is not available. Taken together, these chapters show the diversity of people experiencing care poverty and its various manifestations.

In Chapter 6, Vlachantoni et al examine patterns of met and unmet care needs over time. Drawing on evidence from the English Longitudinal Study of Ageing and making comparisons between different types of older people's social networks, the chapter identifies groups at increased risk of persistent unmet need, with implications for social policy design. They show that both informal and formal care need to increase in order to reduce unmet need, and that policies need to target the most vulnerable networks by providing them with additional care resources.

Survey data are also used in Chapter 7 by Mathew Puthenparambil et al, who compare care poverty among three groups of older people: those who use only formal care services; those who receive only informal care; and those who rely on both formal and informal care. Their results show that in Finland the majority of older people with personal care needs receive a combination of formal and informal care, while those with practical care needs tend to receive only informal care. However, even when older people receive care from a combination of formal and informal and informal sources, this user group is the most likely to have unmet care needs.

Also in Chapter 8, Rostgaard analyses survey data and finds that the coverage of home care in Denmark has fallen dramatically. The results show a significant increase in inadequate coverage of care needs due to an interplay between individual and societal factors, where local political

priorities clash with cultural understandings of how care needs are best met. This points to a substantial change with implications for the core elements of the Nordic public service model, in terms of generosity and universalism, and for the extent of the phenomenon of care poverty and the inequalities it entails.

With Chapter 9, the attention of the volume turns to family carers. In this chapter, Potočnik et al analyse how people from different socioeconomic backgrounds transition into caring and how they navigate their care responsibilities. By analysing the different care trajectories of Slovenian family carers, the chapter finds that the inadequate provision of formal home care has a significant impact on the organisation and navigation of care responsibilities in everyday life, especially in families with a low socioeconomic status who are unable to supplement the inadequate public home care provision with private care services. Care poverty thus overlaps with (income) poverty, as low-income carers often report feeling trapped and overburdened in their role.

In Chapter 10, Leiber and Brüker highlight that not only people in need of care but also carers are at risk of having unmet needs. In their intersectional analysis of the situations of family carers coming from both Western and Eastern Germany, they identify different type-specific unmet needs along an intersectional typology of coping with caring, as well as overarching unmet needs across the coping types. Coping with caring was also found to be different in Western and Eastern Germany, due to structural deficits, but also due to the high level of employment among carers in the East.

In Chapter 11, Aaltonen et al examine a specific but central and rapidly growing group of older people and carers: people with dementia and their informal carers. The chapter combines the analysis of survey data and indepth interviews from Finland and finds that, although people with dementia receive more care than people without the condition, they still have more unmet needs. The authors conclude that the current social and health care system in Finland is inadequately prepared for the complex care needs of people with dementia, leading to unmet needs and care poverty, and affecting the well-being and health of their carers.

Part III concludes with Chapter 12 by Ulmanen who examines 'managerial care', that is, how families secure and manage care for their older members. Faced with the risk of care poverty, family members use their economic, cultural and social capital to try to ensure that care services meet the needs of the older person and reduce their own care responsibilities. This includes identifying what services are needed and whether they are available, accessing and mobilising services, and monitoring and orchestrating services. The chapter concludes that while managerial care has alleviated care poverty for many older people in Sweden, the needs of female carers, in particular, remain unmet.

Finally, Chapter 13, which forms Part IV of the book, draws on the previous chapters and critically discusses current research approaches to understanding unmet needs and care poverty. It summarises the theoretical, methodological and policy lessons learned and also outlines future directions for this area of research. Theoretically, the care poverty framework is seen as a significant step forward, particularly in bridging feminist and disability scholarship. Methodologically, the volume opens up new avenues, for example, by discussing ways of defining care poverty thresholds and measuring the intensity of care poverty. Empirically, new evidence presented in the book shows that care poverty exists even in the most developed welfare states and that socioeconomic status is very closely linked to unmet needs of older people and their carers. The links and even trade-offs between the unmet needs of care recipients and their carers become clear, as does the importance of the socioemotional dimension of care poverty. Policy-wise, there is an apparent need to increase the availability of care, to better tailor support to existing needs, and to recognise and address the needs of carers through adequate support and financial protection. The chapter – and thus the book – concludes with a call for comparative care policy research informed by the care poverty approach.

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