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Introduction

In February 2016 *Helsingin Sanomat*, the largest newspaper in Finland, reported a fire (Hakkarainen, 2016). The fire had broken out in the home of an 87-year-old woman and her 91-year-old husband. As the newspaper interviewed their son, he noted that his parents had health and physical challenges, such as dementia, diabetes, and mobility impairments, which had made their daily life difficult. The son lived elsewhere but visited his parents daily, and the couple also received two daily visits from municipal home care services. Nonetheless, both the son and the home care workers had come to the conclusion that this support was insufficient and the couple was actually in need of residential care.

The son had asked for placement in a residential unit for his parents but had been told by the local authority that his parents did not meet the criteria for institutional care because their needs were not extensive enough. The couple had themselves expressed that they did not want to move to 'a poor house', and this was used by the authorities, who stated respect for individual will as a reason to let the couple remain at home. The son replied that the decision only paid lip service to his parents' self-determination and actually deprived them of their human dignity. His mother did not have energy to go to the toilet, so the home had started

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to smell of excrement. Ill with dementia, his father had started shoving his wife. The son believed that residential care would restore his parents' dignity and joy in life, as earlier even short stays in a hospital had enhanced their condition. Still, his parents were never placed in residential care. Instead, on a Friday night in the end of January 2016, a fire broke out in their home and killed them both.

The media also regularly reports on violence between wearied family carers and the older people in their care. In February 2015, a 71-year-old man in Japan killed his wife who suffered from dementia. As he explained to police, 'I got too tired from looking after her. I wanted to take my own life, too' (Oi, 2015). In November 2019, a 72-year-old Japanese woman killed her 93- and 95-year-old parents-in-law as well as her husband due to exhaustion from taking care of all of them (*Japan Times*, 2019). Such cases have recently become so common in Japan that they have received a term of their own: 'care murder' (*kaigosatsujin*, 介護殺人). They are also recognised in the United States as 'family caregiver homicides' (Cohen, 2019).

In fact, dramatic and tragic accounts of the neglect of older people have been reported from all corners of the world. These older persons have been 'ageing in place', that is, continuing to live in their homes despite increasing need for care. Many had informal family carers, but in the absence of external support, these carers reached their limits. Some even received formal care, but it was insufficient to meet their needs. Each case is unique, and both the factors and contexts that led to tragedy are always specific. But overall, these accounts share a common feature: a lack of adequate care. If adequate support had been provided to these older individuals and their family carers, these news accounts would have never been written. The accounts show how the failure to meet care needs is not without repercussions. This failure imposes serious impacts on quality of life and sometimes leads to fatal consequences.

The purpose of this book is to highlight the critical importance of adequate care and to help direct the attention of researchers and policymakers to the question of whether or not older people who need care in their everyday lives actually receive such support. The book argues that the whole system of long-term care was created to address the care needs of the population and that the question whether this really happens in practice should be a key issue guiding research and policy-making. Are there older people whose care needs remain unmet? If so, who are they and which of their needs are particularly at risk of not being met? What policy measures would help ensure that the care needs of everyone are met in the future?

There is a stream of gerontological literature, mostly from the United States but increasingly from other places as well, that analyses the unmet needs of older populations (e.g., Allen & Mor, 1997; Kennedy, 2001; Busque & Légaré, 2012). These gerontological studies have examined unmet personal and practical care needs primarily at the individual level, measuring their prevalence, related factors, and sometimes their consequences. In the early twenty-first century, unmet care needs have been studied in a growing number of countries in Europe, Asia, and Africa (e.g., Gureje et al., 2006; Vlachantoni et al., 2011; Ashokkumar et al., 2012; Peng et al., 2015).

However, the results of these various studies have not yet been collected together. So, knowledge produced by research into unmet long-term care needs remains highly fragmented. One of the key objectives of this volume is to make an inventory of studies on unmet care needs and summarise their main findings. This stream of literature focuses almost exclusively on older people residing in the community, as does this book. Although cases of inadequate care can also occur in residential settings, research into such settings is very limited. This volume is thus likewise limited to the lack of adequate support only in community settings.

Studies on unmet care needs usually concentrate their analysis on the individual level. Although they regularly include socio-economic factors in their lists of independent variables, this research stream rarely discusses these differences as an expression of social inequalities that reflect disparities of access to formal and informal care across different social groups. Furthermore, study results are not often interpreted in their policy contexts to show interconnections between welfare policy designs and the inadequate coverage of care needs. Such analyses might be expected more from social researchers than from gerontologists, but so far the lack of adequate care has received only limited attention from social scientists.

Over the last few decades, care systems and care policies have managed to capture the attention of social policy scholars. For a long time, welfare state research focused almost exclusively on social security systems. Largely thanks to feminist scholars, however, care has since the 1990s been highlighted as a key field in welfare state research. During that decade, feminist and other social care researchers produced a number of pioneering studies that illuminated similarities and dissimilarities between the care systems of different nations (e.g., Lewis, 1992; Orloff, 1993; Alber, 1995; Anttonen & Sipilä, 1996).

This research stream has continued and further expanded. The last three decades have seen the flow of studies on care systems in Western nations gradually broaden to also include countries in East Asia, Latin America, and other parts of the world (e.g., Colombo et al., 2011; Leichsenring et al., 2013; Ranci & Pavolini, 2013). These studies have considerably extended the level of knowledge on national patterns of care provision. The earlier gap in social policy research has thereby largely been filled, establishing care policy research as a regular major area of social policy analysis. Aside from academic researchers, governments and international organisations such as the EU, the OECD, and the World Bank have also actively produced these studies, as demographic and labour market changes (especially ageing populations, declining birth rates, and growing female participation in the labour market) have remarkably heightened the financial and political significance of care (e.g., OECD, 2005; World Bank, 2016; European Union, 2021).

Upon closer examination of the care policy literature, one may however find that many publications overlap to a large extent. There is a particular set of indicators that is constantly reported: financial resources spent in care service provisions (measured as their share of GDP) and the volume of services (the share of users of both institutional and home care within 65+/75+/80+/85+ age groups) are almost always used to indicate the level of long-term care of a nation. These variables do provide important benchmarks for the international comparison of welfare policies. With figures on social expenditures, nations that invest heavily in care can be distinguished from those countries where public resources are used for other purposes. User rates specific to age groups further show how large parts of the older population are receiving at least some publicly funded support.

Still, knowing the share of GDP used on long-term care does not provide any information on what is done or achieved with those resources. Knowing the number of older people who use residential or home care services does not bring about any understanding of the effects of such services on people's lives. Above all, such variables do not answer the fundamental question of whether care services fulfil their basic function—that is, whether they meet the needs of their users. Care policy studies have mostly focused on analysing the volume of services and associated resources, not the outcome of services on individual lives.

This book aims to address the knowledge gap by collecting findings of gerontological studies on unmet long-term care needs and bringing them into contact with social policy discussions. Older people anywhere around the world may find themselves in a situation where they have substantial care needs but fail to receive adequate support. Like population ageing, the ongoing increase of care needs is a universal and global phenomenon. So, too, is the difficulty in covering needs. At the same time, different societies are in very different positions when faced with providing care for their older populations (WHO, 2015). Understanding unmet care needs in their policy contexts is thus a necessary first step when trying to find ways to tackle them. By collecting available evidence and knowledge from different parts of the world, the book aims to present the state of the art in the study of unmet long-term care needs: what we already know about the issue and where knowledge gaps are, or where further research is most urgently needed.

However, this book does not merely aim to collect existing empirical knowledge. It has also conceptual aspirations. Earlier research on unmet needs has very rarely been connected with research on social inequalities and welfare state policies. In order to build these connections, this book argues that a new conceptual starting point is needed. Bringing a novel perspective to the coverage of older people's care needs, the book introduces and employs a new key concept: *care poverty* (see Kröger et al., 2019; Hill, 2021). This is a situation, exemplified above by real-life examples, where older people need care and support but, for various reasons, do not receive adequate help. In such situations, individual care needs are more extensive than the help and assistance available from formal and informal sources. As a result, at least part of their needs remains uncovered.

Adopting the concept of care poverty highlights how unmet care needs denote the deprivation of a basic human need. As with food and shelter, care is vital for human dignity and even survival. This book further understands care poverty as a serious expression of social inequality, dividing older people into groups of those who have access to adequate care and those who do not. All of this means that, in a world of ageing populations and growing needs for care, the lack of adequate care is a serious issue of primary importance and urgency.

The chapters that follow aim to cast light on the issue of care poverty from different perspectives. *Chapter 2* clarifies the concept and its main features, comparing it to related concepts such as 'care gap', 'care deficit', and unmet needs or poverty. *Chapter 3* builds a framework for the analysis of care poverty. First, it considers the two main ways that care poverty can be measured. Second, it introduces three different domains for care poverty. *Chapter 4* uses the new framework to summarise research evidence available from different countries concerning the key question of how common it is for care needs to remain unmet among older people. *Chapter 5* draws from the framework and existing literature to continue the analysis by looking for factors that are associated with care poverty. *Chapter 6* keeps mapping the state of the art by collecting research evidence on the manifold negative consequences of care poverty. *Chapter 7* connects the empirical results on inadequate care to research on social inequalities, examining how different kinds of inequalities are reflected in care poverty. *Chapter 8* brings in welfare state analysis and discusses the findings on care poverty in the context of different long-term care systems. Finally, *Chap. 9* summarises the key knowledge attained on the phenomenon of care poverty, draws conclusions, and outlines lessons for policy as well as research.

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