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Towards an understanding of care poverty

Kirstein Rummery, Teppo Kröger,
Nicola Brimblecombe and Ricardo Rodrigues

Introduction

In this chapter we will draw together some of the key lessons on care poverty from the theoretical and empirical contributors to this volume. As explained in Chapter 1, care poverty is the inadequate coverage of care needs resulting from a combination of individual and societal factors. However, our intention is not to produce a meta-theory of care poverty. We are aware of the dangers of grand theorising and attempting to create a theoretical framework capable of explaining the experience of giving and receiving care would fail to capture some of the vital nuances of those experiences. However, it is our view that previous theories concerning the giving and receiving of care have not yet adequately explained those phenomena, and it is our intention to push the debate forwards, rather than bring it to its conclusion.

We aim to develop a more theoretically sophisticated understanding of care poverty through examining the empirical evidence and methodological contributions that we have to date. This evidence is by its nature limited to those who contributed to this volume. Nevertheless, the empirical basis of this volume is fairly wide-reaching and covers many care scenarios and contexts. We have explored the experiences of paid and unpaid carers, of inter- and intra-generational family care, of people with dementia who pose particular challenges to theoretical models of care, of contexts where there is paid care widely available and where it is seen in policy terms as a 'last resort', and the intergenerational and intersectional impact of caring. This volume incorporates also different methodological contributions for the analysis and advancement of our understanding of care poverty.

We acknowledge that there are some very notable gaps in our review of the current state of the art in empirical terms. We do not include any chapters looking at care in underdeveloped welfare states or the Global South. Our evidence base for those receiving care is largely older people, and sometimes younger disabled adults – we have not yet explored the issue of disabled children and the interface between care poverty and parenting (however, see Kröger, 2010). And we are by the nature of this volume all academics: although some of us have lived experience of care and care poverty, we are all drawing on our theoretical and empirical research for these contributions. In chapters using qualitative methods, we have directly heard from people experiencing care poverty. However, the voices of those actually living with care poverty remain underdeveloped in our academic analysis. We have also not really explored the situation of formal paid care workers in addressing care poverty other than through policy analysis (for example, in Chapters 6 and 8, but see Mathew Puthenparambil, 2023) and in challenges to existing theory (Chapter 3). Throughout this chapter, unless otherwise stated, 'carers' refers to family/kinship carers rather than paid care workers.

Understanding care poverty from a theoretical perspective

There are several theoretical developments which underpin our ideas about care poverty. The first is the differences between and synthesis of ideas about unmet need, inequalities in care and care poverty. These are interlinked concepts, but our analysis showed that they are not necessarily interchangeable. Kelly, in Chapter 3, examines the idea of 'unmet need' and points out that this term has historically and in policy analysis always meant the lack of provision of a service to meet need – allowing that this could be a formal health or social care service, or unpaid care, or a mixture of both. However, as several writers in this volume point out, the provision of care does not necessarily in itself meet needs. The issue of care poverty is one of structural significance, not just private relationships.

Moreover, as Mathew Puthenparambil et al point out in Chapter 7, in conceptualising unmet need both academics and policy makers have tended to focus on intimate personal care needs – what are commonly referred to as the Activities of Daily Living (ADLs), based on Katz et al (1963). These are highly medicalised and impairment/body focused and are considered to be key life tasks that people wishing to live 'independently' need to be able to accomplish, such as eating, bathing and dressing. Being able to do these things – with or without care – offers a very limited life that is about existing rather than social participation. Taking on Sen's (1999) poverty framework, these would be equivalent to 'functionings', while a broader understanding of what is the aim of care would also include what Sen terms as 'capabilities' – activities that are about community engagement and self-determination – namely by including also Instrumental Activities of Daily Living (IADLs) (see Lawton and Brody, 1969). The inability to carry out ADLs *and* IADLs is therefore, under care poverty theory, a situation requiring a political response that is about addressing structural inequality and social citizenship, not simply providing a subsistence level of care.

The provision of care to address care poverty is uneven, with consequences for inequality of both carers and those who need care. The idea of a care poverty threshold, as explored by Medgyesi et al in Chapter 5, further engages with the inequality of care poverty. By treating care poverty in the same way as material poverty, there is an absolute threshold below which it is politically untenable for a citizen to fall. Medgyesi et al further develop this idea by exploring the concept of the intensity of care poverty: not only it is multidimensional (much as material poverty is no longer seen as being simply about income) but a complex interaction of the individual (medical/impairment) and the structural (social divisions, material poverty, networks, practical and emotional support). As Potočnik et al discuss in Chapter 9, there is a strong overlap between care poverty and material poverty, and how individuals can manage and address their care poverty is linked to social networks as well as income – inequality in access to care exists across several domains.

The second theoretical approach underlying our ideas about care poverty is the tension between feminist and disability theory in the area of care. Feminists have historically focused on the labour – both emotional and physical – demanded of women when providing care. Disability theory has focused on the exploitative nature of that care – particularly when delivered by unpaid family carers. Instead, they have conceptualised the right to receive care as one of social citizenship: like other welfare provisions, it should be seen as a resource to enable social participation. Rummery argues in Chapter 2 that the advantage of care poverty as a conceptual lens over both feminist and disability theory is that the provision of care becomes a political, rather than a private, issue. It is about the social citizenship of both carers – their right to not suffer material poverty or ill-health that would prevent social participation – and of those who need care – their right to self-determination, well-being and support that enables social participation. Moreover, as Vlachantoni et al discuss in Chapter 6, care poverty includes a socio-emotional dimension – what feminists would recognise as the relational aspects of caring (linked, for example, to emotional labour or the distinction between caring about and caring for), which has its counterpoint in the emotional poverty of being without sufficient care.

The empirical basis for care poverty

Rostgaard in Chapter 8 demonstrates that the reduction of formal care provision is not necessarily matched by family care filling the gaps, particularly for those with more complex care needs. Care poverty in this case can be said to be increasing even in one of the most developed and highly state-subsidised care economies (Denmark in this case). In another highly developed welfare state with high levels of public financing of care

(Finland), Mathew Puthenparambil et al demonstrate that care poverty is highest among those who are getting both formal services and family/kinship care – so even the combination of these resources is not enough to address the care poverty of those with the highest levels of need (Chapter 7).

Aaltonen et al in Chapter 11 confirm this finding with regards to people with dementia and their carers. They find that the formal home care system is insufficiently prepared for the complex care needs – particularly the socio-emotional needs – of those with dementia and their carers. This is an interesting finding, and challenging to Rummery's conclusion in Chapter 2 that the state provision of personalised formal care would address the theoretical and practical tensions that exist when reliance is placed on family care to address care poverty. Namely, that state-provided formal care is vital to address the gendered costs of family care and the self-determination needs of those who need care. Family care is largely, but not exclusively, unpaid care by women and thus has gendered implications for material poverty and social inequality. As families (as Rummery in Chapter 2 points out) are often the only place where the socio-emotional needs of people with dementia can be met to address care poverty, there is a corresponding concern that this places a huge socio-emotional burden on family carers that the state/formal care cannot easily address.

As noted before, none of our case studies includes the experiences of the parents of disabled children, tasked with providing both practical and socio-emotional care for their children through parenting and caring, but these too would likely find themselves in a similar situation: state or formal care cannot easily step in and relieve the burden or address the care poverty of disabled children.

In Chapter 9, Potočnik and her colleagues show that the weak availability of formal home care in a less developed formal care economy (Slovenia) has significant consequences for the care poverty of lower-income households. This is an interesting finding as it clearly demonstrates the links between material poverty, the lack of social capital and care poverty. Leiber and Brüker in Chapter 10 demonstrate further evidence of this: by drawing on a study comparing the situation in East Germany (with former high levels of state support) and West Germany (with a reliance on a mix of family and state support) they show that an intersectional approach is needed to understand the complexity of care poverty even within the same country, and this needs to take into account different political and cultural histories.

Finally, Ulmanen in Chapter 12 discusses the idea of 'managerial care' and reminds us that care itself is not limited to giving assistance with ADL or even IADL tasks: it can also involve the accessing of systems, management of the intersections between formal and family care, and navigating the wider welfare state to support those who might be living in both care poverty and material poverty. This emotional labour is highly gendered and has an impact on the social and emotional well-being of carers, as well as having time and resource costs for them.

Defining and measuring care poverty

'Need' remains a key and disputed concept in the context of care poverty. Hill et al in Chapter 4 provide a detailed account of the different disciplinary approaches to 'need' from different etiological perspectives (harms, rights, collective obligations, individual autonomy, empowerment, choice, distribution and poverty, to name a few). Besides these approaches, a dichotomy remains between self-assessed and third-party or externally assessed need, with a strong tradition from health and other disciplines to rely on self-assessed need. Yet, as Hill et al in Chapter 4 show in their review of needs-assessment instruments, unmet needs and their causes (particularly systemic ones) are seldom included in needs assessment instruments. Moreover, none uses the concept of care poverty or attempts to define thresholds for unmet needs. A necessary next step is therefore to bring care poverty into assessment – the real world of practitioners and street-level bureaucrats, not least of all because 'assessment tools shape care providers' and care receivers' perceptions of needs to be met through services, priorities and "policy problems"' (Chapter 4, based on Dickson et al, 2022).

Medgyesi et al in Chapter 5 show that the definition of needs is also key for the advancement of methods to assess care poverty. The concept of care poverty highlights the systemic factors that underline the mismatch between needs and care, and as access to (affordable) care is often based on an assessment of needs (which presupposes a definition of it), this is indeed a key concept for care poverty.

The concept of care poverty is underpinned by a structuralist approach (Kröger, 2022). Comparing care poverty across different long-term care systems or countries, or even within countries before and after major policy reforms, could shed light onto the determinants of care poverty and successful measures to address it. This area, however, remains relatively unexplored in the literature. While there is some discussion about the use of self-perceived unmet needs for international comparison (for example, due to differences in the anchoring of expectations), Medgyesi et al in Chapter 5 point to the potential for relative measures of care poverty to enable cross-country comparisons.

Building on the vast literature on (income) poverty, Medgyesi et al point in Chapter 5 to some dimensions that can add to the relevance of the concept of care poverty. Two of them stand out. The first of these is 'intensity of care poverty', defined as 'how distant a particular individual may be from having their needs met by care'. The second is the distinction between different types or reasons for care poverty, mirroring what is already done for unmet needs for health care (for example, the distinction between unmet needs due to financial reasons, unavailability, lack of quality). Both are of particular relevance to guide policy. Medgyesi et al in Chapter 5 did not review existing data sources, but while care poverty may require new methods or metrics that enable this concept to be impactful in policy and ultimately people's lives, it is nonetheless clear that it may also require new data and indicators. For example, when assessing care use, many of the most commonly used international survey datasets today do not or only imperfectly account for quality of care, intensity and frequency of care used. This is a parallel development that needs to take place as well.

Among the causes of care poverty, affordability ranks as one of the most relevant across different long-term care systems. For example, Potočnik et al in their analysis of care trajectories among care dyads in Slovenia (Chapter 9) and Mathew Puthenparambil et al in their study on care receivers in Finland (Chapter 7) concur in the relevance of affordability. In the former study, affordability is a crucial reason for unmet needs, not only among care recipients but also among carers. In both cases, care recipients were using a mix of formal and informal care, which highlights that informal care cannot always fully fill the care gap left by unaffordable care services. In both studies, affordability issues and unmet needs appear to be more prevalent among less affluent individuals despite targeting policies in place (for example, income-related out-of-pocket payments or exemptions from payments based on income).

Mathew Puthenparambil et al in Chapter 7 present higher needs as a determinant of care poverty, but it is possible that the causality runs the other way around, with care poverty as a determinant of poorer health outcomes (that is, as an enhancer of needs) (cf Komisar et al, 2005 and other studies cited in Chapter 6). This calls for longitudinal studies, which would enable us to see the effect of care poverty over time, while at the same time analysing another relevant metric: persistent care poverty (Chapter 6).

The focus on affordability may, however, also reflect a 'streetlamp effect' in existing data, especially quantitative datasets, which for the most part fail to distinguish between different reasons for care poverty. Qualitative studies, on the other hand, have the ability to provide us with insights into different reasons for care poverty based on people's own experiences. Potočnik et al in Chapter 9 show that besides affordability, lack of available care on particular days or time periods (for example, holidays and vacations) is also a key reason for unmet needs. Other reasons for unmet needs uncovered by this qualitative study include tasks that professional carers are unable to carry out (for example, certain personal hygiene tasks or nursing care). Filling those gaps or unmet needs remains a key motivation for the provision of informal care. Kelly shows in Chapter 3 how much of these gaps are routed in the care economy (Peng, 2018) and how it is organised, and very importantly, financed. Going back to the study of Potočnik et al on care dyads (Chapter 9), it is also clear that unmet needs among care recipients have clear consequences for caregivers, exacerbating care burden and creating their own unmet needs.

Kröger's (2022) initial definition of care poverty considered different dimensions of care poverty such as personal and practical care poverty. The relevance of this distinction between different dimensions of care poverty, but also its variety, is well expressed in a number of findings that highlight different trends, prevalence of unmet needs and even possible underlying causes for the different dimensions of care poverty (Chapters 6, 7 and 9). For example, Potočnik et al show in Chapter 9 that needs for social interaction and socialisation are consistently left unmet by care services, a finding that is echoed by other studies (for example, Van Aerschot et al, 2022).

Policy and practice implications of our findings on care poverty

First, it is clear that the theoretical idea of care poverty – distinct from unmet need – has provided an extremely useful development in trying to make sense of the work of care, from both a structural and socioeconomic perspective, and from an individual relational and socio-emotional perspective. We can clearly see how care poverty is both a political and theoretical lens that can add nuance and a deeper understanding of the complexities of care in modern developed welfare states.

This has clear implications both for policy and practice in our case study welfare states. Those who are living in care poverty – whose needs are not met and who are socially excluded due to the lack of adequate care – need to be able to access and navigate existing care and support systems more easily. The complexity of formal support, with responsibilities divided between national, regional and local governments, public and private providers, and health, long-term care and welfare systems, is disastrous and adds bureaucratic barriers to addressing care poverty, particularly for those with complex support needs. Existing support also needs to be better matched to existing needs, particularly where those needs are variable and change over time.

There is a political as well as a theoretical discussion to be had about who is responsible for providing care that would address care poverty. Feminist and disability theory and evidence to date would suggest that the provision of formal paid personalised care services is the optimal route to address care poverty of those who need care and support without increasing the material and socio-emotional poverty of carers – resulting in high levels of women's poverty. However, we already mentioned how the socio-emotional element of care poverty of those with dementia and those with little material capital may be best addressed by family/kinship care – and in fact, it may not be possible for formal provision of services and support to provide adequate care to address care poverty in these situations, although improvements in formal care such as the ability and time for care workers to build and develop relationships and have time to spend on socio-emotional support may help. If the responsibility is to lie with family carers, the effects of this need to be recognised and addressed through adequate support and financial protection.

Better policies to address care poverty would recognise the need for, and the benefits of, investment in long-term formal social care provision. Part of this needs to be in recognition of both the costs and the political inacceptability of high levels of care poverty, particularly in wealthy developed welfare states. However, even highly developed formalised care economies are increasingly relying on family/kinship care – and liberal and familial based welfare systems always have relied on family/kinship care at the expense of gendered inequality. The empirical findings presented here show the limits of such policy in addressing care poverty, as those using a mix of care services and informal care were often more likely to experience care poverty, while at the same time highlighting the issue of care poverty among informal carers. For these reasons, policies to address care poverty in all developed welfare states need to include the voices of, and meet the needs of, family/kinship carers and not just those who need care and support.

Finally, it is worth noting the important lessons for policies indicated by the work of Hill et al in Chapter 4. They note that policy is often driven not just by ideological and empirical aims, but also by what is measurable and achievable, due to a push towards evidence-based policy making (Oliver and Cairney, 2019). There is a significant need for interdisciplinary approaches to theorising, researching and measuring care poverty. Measures that are somewhat limited, and questionable from a disability theory perspective as being overly individualised and medicalised, such as ADLs and IADLs, are universally used because they are simple and easily measurable without any significant challenges to the normative frameworks that underpin policy with regards to care poverty. If we are to develop new policies that are universal and recognise the tensions inherent in addressing care poverty, then we need to address the normative frameworks underpinning policy, and correspondingly develop new ways of measuring when we have got there. When the concept of care poverty was introduced, Kröger (2022) linked it to a 'policy failure' and it is therefore in and to public policies that we must impact and return to if we are to correct these failures and enable older citizens and their carers to have their needs met adequately.

A blueprint for future work

We have demonstrated in this volume that the development of care poverty has a theoretical sophistication that can get us beyond understandings of unmet need and inequalities, as well as providing a conceptual synthesis between feminist and disability theory. We have also demonstrated that this conceptual clarity can be applied to a range of academic challenges, from researching to measuring to theorising care poverty and its policy implications. Our empirical findings indicate that intersectionality is an important element of identifying and addressing care poverty. It is not possible to divorce people from their social, cultural and political context, so we cannot ignore that different social divisions such as gender, class, age and ethnicity have differential impacts on both the incidence of, and the qualitative experience of, care poverty.

However, this volume is very much the beginning rather than the end of a conversation. There are several areas left unexplored in this collection which require urgent attention. First, our developing theoretical understanding of care poverty needs to continue evolving. While we have tested the theory out in various empirical scenarios, there are several important perspectives missing from our theoretical development. We need to test these theories out in situations where the challenges of identifying and measuring care poverty, as well as designing solutions for it, are complex, just as the lives of people who are experiencing and trying to tackle care poverty are complex. It is clear that material poverty and care poverty are inextricably linked, and the ability to address one affects the ability to address the other. We need to think further about ideas that underpin our understanding of care poverty, in particular conceptions of need, absolute and relative care poverty, and social citizenship, while at the same time developing and testing further indicators to measure care poverty (for example, intensity and persistence of care poverty).

Several voices and perspectives are missing from the theoretical developments begun here. We have not drawn on evidence and stakeholders living in underdeveloped welfare states, or in countries where material poverty is endemic and systematic. We have relied primarily on academic voices to critically engage with the theories and evidence but, in the future, more co-production with carers and those who need care is needed.

Second, the theoretical gaps in our knowledge are also matched by the empirical gaps. In this volume we have managed to raise more empirical questions than we have answered. What are the implications of care poverty for groups of people who need care but who cannot easily advocate for themselves in navigating both formal and family/kinship care? For example, there are challenges in applying theoretical ideas around care poverty and self-determination to people with dementia, some groups of learning disabled adults, those in extreme mental distress and disabled children. Do our theoretical framings stand up to empirical enquiry with these groups?

We also do not know much about the application of care poverty theories to the lived experience of formal care workers. Does it help us understand their lives? What role do they play in addressing care poverty? While there is a substantial evidence base for practitioner challenges, little of it to date draws on care poverty theory as an explanatory factor, nor as a framework to develop better policies and practices for this group (see, however, Mathew Puthenparambil, 2023). Most empirical research presented in this volume relied on secondary data that was not purposely developed to capture important dimensions of care poverty, such as its causes. Some of the qualitative studies unearthed possible important dimensions or causes for care poverty that must be further explored in the future with purposely collected data. Knowing the causes of care poverty and inequalities in care poverty is crucial in knowing how to address it.

There are many interesting single country case studies presented here, but there is a dearth of comparative care policy research that is informed by care poverty theories. What kinds of systems and practices address care poverty? What kinds of systems and practices increase the risk, and the detrimental effects of, care poverty? What measures of care poverty are better suited for cross-country comparisons? How can the theoretical and empirical contribution of care poverty be used in an ageing world to address the widening gap between those at risk of and living in care poverty and those who are not?

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