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Framework of Care Poverty

Care is a complex phenomenon that is difficult to measure. In order to know whether there is an imbalance between care needs and their coverage, two things are required: (1) knowledge of care needs, and (2) an assessment of the match between needs and available support (García-Gómez et al., 2015). The level of available care resources alone does not define care poverty. It is only together with knowledge about the level and kinds of needs that an understanding of the match between care needs and resources can be achieved.

There are already complications with the first of the above-mentioned tasks, as care needs are a demanding object to capture. In poverty research, it is possible to make a list of basic goods necessary for survival and subsistence and then determine a monetary value for this basket. But what items should be placed in the basket of basic care needs, and how should they be weighted? Research literature shows a variety of different kinds of needs and a range of ways that they have been measured in studies of unmet needs. How can this diverse array of definitions and approaches be handled in order to reach a coherent understanding of the level of care needs?

T. Kröger, *Care Poverty*, Sustainable Development Goals Series,
https://doi.org/10.1007/978-3-030-97243-1_3

The second task is not any easier. It is far from clear how to evaluate whether or not the care needs of an older person have been met. There are two main competing methodological approaches used in studies of unmet needs. The first one is said to measure unmet needs 'subjectively' because it is based on self-reporting from older people rating their own care as inadequate; the second one measures unmet needs more 'objectively' because older people are not asked about the sufficiency of the support they receive (Lima & Allen, 2001). However, both approaches have been criticised—the first for a potential self-reporting bias, and the second for underestimating unmet need by failing to include situations in which older people receive insufficient help (Lima & Allen, 2001; Shea et al., 2003). There is no consensus among researchers how the 'unmetness' of care needs should be assessed.

To deal with these complications, this chapter outlines a framework that helps organise earlier literature on unmet needs and summarise its key findings. In order to achieve the analytical clarity needed here, care needs are organised under three different domains, which then leads to a categorisation of three different domains for care poverty. As mentioned above, earlier research has measured unmet needs in two primary ways. This adds a methodological dimension to the framework. The chapter thus builds its framework for the study of care poverty on three domains and two measurement approaches.

Domains of Care Poverty

Discussion of the nature and definition of care has continued for decades. According to Fine (2007, p. 2), a definition for care has remained elusive because 'it refers at once to an ideal set of values and a series of concrete practices'. Many writers, especially within the ethics of care literature, have emphasised the normative dimensions of care. For example, Sevenhuijsen (1998, p. 19) views care as a social practice in which different sorts of moral considerations and vocabularies may be expressed. Other writers have focused more on the tasks or activities that are

included. For instance, Knijn and Kremer (1997, p. 330) define care by stating that it 'includes the provision of daily social, psychological, emotional, and physical attention for people'. A definition that is likely the broadest comes from Fisher and Tronto (1990, p. 40), who see care as 'a species activity that includes everything that we do to maintain, continue, and repair our 'world' so that we can live in it as well as possible'—adding that the 'world' refers here to 'our bodies, our selves, and our environment'.

The approach of this book follows the latter task- and activity-oriented perspective, though in a much narrower sense than the definition provided by Fisher and Tronto. Here, the focus is on the practices that are performed in order to meet the care needs of older people. This is not to deny the normative character and moral foundations of care. It is indisputable that care is closely interrelated with its cultural and normative contexts (e.g., Daly & Lewis, 2000; Pfau-Effinger, 2005). But as this book focuses on the lack of adequate support, it is necessary to concentrate on care as concrete assistance given to older people in order to meet different kinds of care needs.

As mentioned earlier, there is already a considerable and growing body of literature on the unmet care needs of older adults. Yet due to its terminological and methodological diversity, summarising its results and describing its state has been difficult. Part of the problem has been how different studies take different care needs as the basis for their analysis. When referring to unmet needs, researchers could have taken more care to elaborate exactly what needs they were analysing. Rather than mixing all needs together, could they be categorised into certain groups or domains? Could such categorisation bring more conceptual coherence and clarity, making it easier to accumulate knowledge? Specific kinds of unmet needs may be determined by specific kinds of factors and processes. Thus, a more detailed analysis might help researchers better understand the origins of care poverty. For the purpose of this book, three different domains for care poverty are distinguished: personal care poverty, practical care poverty, and socio-emotional care poverty.

Personal Care Poverty

In spite of the variety and ambiguity of care needs, gerontologists have been actively trying to define and measure them. In the early 1960s, Katz et al. (1963) in the United States developed the scale of ADLs. This has since become by far the most popular way to capture the needs of older people. In their original article, the researchers listed six basic daily functions (bathing, dressing, going to the toilet, transferring that meant moving in and out of bed and chair, continence, and feeding) and built up a summary index for these six activities. They created their approach specifically to evaluate the outcomes of treatments and the prognosis of older hip fracture patients. However, they also recommended their model for broader use. Their ambitions were certainly realised as their instrument has been applied to general use in long-term care research and practice all over the world.

One key reason why the ADL approach has become so widely and internationally applied is that the invention of Katz and his colleagues shifted attention away from specific health conditions and impairments to focus instead on functional abilities and their limitations. From the perspective of care needs, it is not so important to know why the functional abilities of older people have narrowed. Instead, it is crucial to learn what the person in question is and is not able to do. Medical care focuses primarily on illnesses, trying to diagnose and cure them. But long-term care concentrates on providing assistance for those everyday activities that older persons are unable to perform alone. The ADL framework has suited this purpose well.

The ADL approach is widely used not only at the practice level to assess the needs of older people, but also in long-term care research. The framework has been developed into several versions and undergone several modifications with slightly different lists of daily activities. Nevertheless, ADLs remain the starting point for most studies on unmet care needs. As ADLs include basic everyday activities such as eating, dressing, and toileting, limitations in performing these activities lead almost unavoidably to care needs that must be covered either informally or formally. When these needs are not met, the well-being, health, and ultimately life of the older person fall under threat.

Due to their fundamental importance, several researchers have described these activities as the basic activities of daily living (BADLs) or personal activities of daily living (PADLs) (e.g., Tennstedt et al., 1994; Davey et al., 2013). Whatever term is used, limitations in performing these activities create needs for personal care. Due to their importance for survival and well-being, they form the basis of all care needs. For the same reason, the inadequate provision of support for these needs can be seen as the hard core of care poverty. Here, a lack of coverage for these needs is called *personal care poverty*. It is understood as the first and most significant domain of care poverty.

Practical Care Poverty

The most important addition to the ADL approach was introduced by the end of the 1960s. Lawton and Brody (1969) launched another list of activities, the IADLs. They argued that the ADL scale was necessary but insufficient to assess older and disabled people's opportunities to continue to live in their homes and avoid ending up in institutional care. They then created a list of more complex daily activities and skills to supplement the original ADLs. Lawton and Brody's IADL list included the ability to use a telephone, shop, prepare food, do housekeeping and laundry, use some mode of transportation, take responsibility for personal medications, and handle finances. In accordance with typical gender roles of the time, shopping, cooking, and doing laundry were thought to assess the functional competence of women, and the use of transportation and ability to handle money were understood as suitable indicators for men's level of competence (Lawton & Brody, 1969, p. 180).

The IADLs considerably broadened the understanding of functional skills that are necessary in everyday life. Rather than focus solely on bodily care, the IADLs showed that the practical needs of daily life were also important. Unmet IADL needs impacted a person's quality of life, though usually they have a less adverse effect on individual physical integrity or health status than unmet ADL needs (Vlachantoni et al., 2011). Although IADLs are not as fundamental as ADLs in terms of daily

activities, daily life becomes very difficult without these abilities. IADLs also usually recognise functional difficulties at an earlier phase than ADLs. Difficulties in performing practical tasks emerge before difficulties in personal care tasks. This is because the IADLs are located at a higher level of function than the ADLs, requiring not just considerable physical but also mental capacity (Vlachantoni et al., 2011).

Together, the ADLs and IADLs form the basic toolbox and dominant method for assessing and evaluating the long-term care needs of older people. They are widely used in different parts of the world, even though their application often requires some adaptation and update for specific cultural and societal contexts. For example, the differential treatment of women and men when assessing IADLs has become outdated and abandoned (Williams et al., 1997). The role of IADLs has been to highlight that, aside from limitations in basic self-care, difficulties in performing practical household tasks can also cause care needs. Though not immediately life-threatening, inadequate coverage of these practical needs still poses a major risk to the well-being and health of older people. Here, a lack of help in meeting these needs is called *practical care poverty* and seen as another major domain of care poverty.

Socio-emotional Care Poverty

Older people's needs however go beyond personal and practical care needs. The I/ADL framework has been especially criticised for failing to capture social and emotional needs (e.g., Sihto & Van Aerschot, 2021). Feelings of belonging and connection to others contribute to the meaning of life for older adults. They are positively associated with health status and can solve the problems of alienation, isolation, and loneliness (Ten Bruggencate et al., 2018). When the social needs of older people are unsatisfied, this jeopardises their quality of life and can lead to mental and physical health problems. For example, research shows that older people's unmet social and emotional needs are connected to depression (Someşan & Hărăguş, 2016).

Social interaction easily decreases in old age, when mobility impairments start to limit opportunities to leave the home and thus meet new

people (Gabriel & Bowling, 2004). Furthermore, a growing number of communication impairments can make the maintenance of social relations difficult for many in old age. Satisfaction of older people's needs involves emotional support (Rodrigues et al., 2012, p. 15), but the availability of emotional support regularly decreases in old age due to retirement or the deaths of partners and friends. Furthermore, formal care services often focus exclusively on meeting personal care needs at the expense of the social and emotional needs of older people (Meagher et al., 2019). Overall, older people are at particular risk of not having their psychosocial and emotional needs met.

Studies on the unmet social and emotional needs of older people have often been carried out in the context of specific illnesses or health problems, such as cancer (Williams et al., 2019), HIV (Ogletree et al., 2019), dementia (Hansen et al., 2017), and joint pain (Hermsen et al., 2018). This research routinely focuses on how different groups of health care professionals respond to the risks posed to the social and emotional well-being of their patients. The usual finding of such studies is, variably and overall, not so well (e.g., Convery et al., 2017; Hansen et al., 2017). In social and health care, psychosocial needs are regularly prioritised at a lower level than physical needs. Often, professionals will even say that it is not their responsibility to provide psychosocial support or that the task belongs to family and friends (e.g., Hansen et al., 2017). However, many older people do not have access to social and emotional support from family or social networks.

Within gerontology, concepts in the area of social relations that have received the most research attention are social isolation and loneliness. Social isolation is usually defined as lack of social contacts. For example, Wenger et al. (1996, p. 333) define social isolation as 'the objective state of having minimal contact with other people'. Loneliness has been defined, for instance, as 'a self-perceived state in which a person's network of relationships is either smaller or less satisfying than desired' (Jones, 1981, p. 295). For both concepts, there is a multitude of slightly different definitions. In general, however, social isolation has been understood as an objective characterisation of the weakness of a person's social networks. In turn, loneliness has been seen as a person's subjective perception or experience of social relationships of inadequate quality and/or quantity.

While social isolation is not necessarily always experienced as negative, loneliness is. Some people may, in some situations, prefer solitude at least temporarily (Yang, 2019), but loneliness is, according to De Jong Gierveld et al. (2018, p. 391), the 'negative experience of a discrepancy between the desired and the achieved personal network of relationships'. Such a definition comes very close to the notion of care poverty: when it comes to an essential area of human need, there is a gap between the level desired and the level achieved. Not surprisingly, loneliness has been connected to unmet social and emotional needs. For example Shaver and Buhrmester (1983, p. 259) see it as 'an emotional state that arises when certain social needs go unmet'. Loneliness is thus understood here as an expression of unmet social or emotional needs and, thus, of care poverty.

Whatever terms are used for these needs—whether social, emotional, and psychosocial needs, or needs for belonging, intimacy, social interaction, and social support—gerontological research has made clear that they are crucial in old age. The risks of having these needs unmet increase with age as many issues make social interaction more difficult for older people, especially when they start to have mobility or communication difficulties. Needs for respect, love, and belonging do not disappear in old age. When these needs go unsatisfied, they carry negative implications for the physical and mental well-being of older people. Sometimes the situation even leads to a suicide attempt (Lebret et al., 2006).

Due to their importance, unmet social and interactional needs should be included in the care poverty framework. While their measurement is even more complicated than that of unmet personal and practical care needs, this is not a valid reason to exclude them from the framework. Here, unmet social and emotional needs are understood as a third domain of care poverty called *socio-emotional care poverty*, complementing the domains of personal care poverty and practical care poverty.

In this book, the examination of care poverty is limited to these three domains. However, it is recognised that these domains do not cover all of the needs of older people. Unmet health care needs might well be listed as another domain. So, too, could support needs caused by cognitive impairments. But here, the focus will remain on personal, practical, and socio-emotional care needs because these three domains are essential for everyday life of older people. There is also a substantial body of research

literature for each domain that can be mined to summarise key findings on the rates, factors, and consequences of care poverty.

Measurement of Care Poverty

After identifying care needs, the research has to discover whether an imbalance exists between these needs and received support. It is crucial to know whether available informal and formal care manage to cover the care needs of the older population. Knowledge of care needs is not enough by itself. Neither is information about the availability of formal care, not even when combined with the availability of informal care. Care poverty is fundamentally about a relationship between needs and resources. So, the question is whether available informal and formal care cover existing care needs. When measuring care poverty, the key is to examine this match between needs and resources.

The definition and measurement of poverty has been a source of debate for more than 150 years. At present, there are many competing definitions and subconcepts, each with their own operationalisations. These discussions are not merely academic in nature as different measurements produce different results, and different results have different implications for policy (Hagenaars & De Vos, 1988; Laderchi et al., 2003). Many poverty instruments measure the level of individual or family income and, focused on resources, do not necessarily examine needs. However, some poverty measurements do conceptualise poverty as a gap between needs and resources.

Seebohm Rowntree's (1901) seminal study showed that the incomes of more than a quarter of the population of York were insufficient to secure a subsistence level of existence, that is, to purchase the basic necessities of fuel, light, rent, food, clothing, and both household and personal items. Rowntree defined his poverty line based on careful analysis of the cost of these necessities. The *basic needs perspective* later followed the same line of thinking, defining poverty as a deprivation of the absolute minimum resources necessary for long-term physical well-being (Streeten, 1981). *Absolute poverty* was similarly defined by the Copenhagen UN Social Summit as meaning the severe deprivation of basic human needs (UN,

1996). Unlike those poverty measurements focused solely on income, the above-mentioned approaches have understood poverty as a relation between needs and available resources. In order to measure care poverty, a similar approach is necessary.

Aside from absolute poverty, the concept of *relative poverty* is also worthy of attention when thinking about the measurement of care poverty. Raiz (2006) used the terms absolute and relative health care poverty in her analysis, and Vlachantoni (2019) wrote about absolute and relative unmet need. For relative poverty, taking the social environment into account is key: the poverty line is defined relative to a given context (Laderchi et al., 2003). The national context is used as a frame of reference because people's material resources are compared to the general level within each nation. Here, these two poverty concepts—absolute poverty and relative poverty—are applied to the study of care poverty.

Absolute Care Poverty

Despite the variable nature of long-term care needs, gerontological research has aimed to capture them—especially through the use of the I/ADL framework. Gerontologists have also developed methods to measure whether or not these needs are met. Data from these studies come from questionnaire surveys that include questions about the limitations of older people as relates to ADLs and/or IADLs. They also include questions about whether the respondents receive informal or formal care.

In these studies, one usual way to determine whether older people have unmet needs is to categorise respondents with I/ADL limitations into two groups: those who have limitations in their functional abilities and receive at least some informal or formal assistance, and those who have limitations in their daily activities but do not receive any informal or formal help with these activities. The second group is then defined as having unmet needs, while the first group is understood as having their needs met. In this case, unmet needs are defined as the presence of care needs (based on I/ADLs) in the absence of any kind of support for these needs from family members, social networks, and public, non-profit, or for-profit services (e.g., Tennstedt et al., 1994; Lima & Allen, 2001).

Vlachantoni (2019) calls the situation where an older person has care needs but fails to receive any formal or informal support as *absolute unmet need*. She defines this term as 'a difficulty with a certain task combined with the complete lack of support with such task' and explains that she chose this approach for her study because it points to a part of the older population most in need of support (Vlachantoni, 2019, 661). This 'absolute' approach to operationalise unmet care needs has been used by many other researchers, as well (e.g., Allen et al., 2014; Davey et al., 2013).

The term absolute unmet need comes close to the notion of absolute poverty. Absolute poverty was defined by the UN 1995 Social Summit as the severe deprivation of basic human needs, including food, safe drinking water, sanitation facilities, health, shelter, education, and information (UN, 1996, p. 38). Absolute unmet need means the deprivation of any kind of support for basic care needs: even people unable to adequately perform ADLs such as toileting and feeding fail to receive formal or informal care. In this volume, the full absence of help for care needs is called *absolute care poverty*.

Relative Care Poverty

Despite its clarity, classifying people into two clear-cut categories, the absolute method for studying unmet needs does not satisfy all researchers. The approach captures those whose needs are left fully uncovered, but only those. People whose needs are only partially covered are not included in the definition. Referring to absolute care poverty as 'objective unmet needs', García-Gómez et al. (2015, p. 150) encapsulate this shortage by saying the measurement 'may not capture those individuals receiving insufficient services, as the probability of objective unmet needs when the individual receives any type of service is zero'. Aside from excluding those older persons who receive any formal care service, the absolute approach also excludes all those who receive any informal care. Such a measurement leads to significant underestimation of the extent of unmet needs because receiving some informal or formal support does not guarantee that the older person receives sufficient care and assistance (Shea et al., 2003, p. 716).

As a response, some researchers have developed another method to identify unmet needs: in addition to asking respondents about limitations on their daily activities, they are also directly asked whether they receive adequate support to cover their care needs. In this approach, all who answer that they do not receive sufficient care are categorised as having unmet needs—regardless of whether they receive any formal or informal care (see, e.g., Williams et al., 1997; Lima & Allen, 2001). Consequently, this method captures unmet needs more comprehensively than the absolute approach.

However, this measurement approach has been claimed to suffer from self-reporting bias (García-Gómez et al., 2015; Yang & Tan, 2021). Self-reporting is based on subjective perceptions, and these are said to be conditioned by contextual characteristics, such as characteristics of the long-term care system or cultural norms and values concerning care responsibilities (Rogero-García & Ahmed-Mohamed, 2014, p. 405). Due to their professional training and experience, assessments made by professionals are sometimes considered more accurate than self-reporting.

But when researchers asked long-term care staff to complete the surveys and then compared those answers to the ones self-reported by older people, they found that it was the staff—not the older persons—who more often reported unmet needs (Morrow-Howell et al., 2001). After Brimblecombe et al. (2017) likewise asked not just the older adults but also their informal carers to fill the questionnaire, the researchers noticed that older people underestimated the level of needs and unmet needs compared to their carers. Researchers have somewhat dissimilar views on how these differences should be interpreted and whose evaluations are more objective in the end. Rogero-García and Ahmed-Mohamed (2014) argue that older people's self-reports are more reliable than proxy respondents. Manton et al. (1993), as well, state that proxy respondents are less accurate in reporting needs. On the other hand, Morrow-Howell et al. (2001) conclude that the ratings from both groups are valid but not interchangeable, because they are based on different standards and different values. Still, one thing seems to be clear: in general, older people do not overestimate their care needs and unmet needs.

Some researchers have used the term 'subjective' when referring to this self-reporting approach and the term 'objective' when referring to the absolute approach (e.g., García-Gómez et al., 2015; Laferrère & Van den Bosch, 2015). But while these two terms may be applicable in poverty research (Siposne Nandori, 2014), they do not fit in the analysis of unmet needs. In poverty research, material resources can be quantified and measured in an objective manner. In care research, however, it is questionable whether it is possible to measure care needs and care resources objectively due to their interpretational character. Even the reporting of I/ADLs is based on human perceptions. The same goes for the receipt of informal and formal care: for example, distinguishing informal care from other family interaction is complicated and based on interpretation. Measurements for care always depend on human observations and interpretations, which then are susceptible to influence from cultural and societal contexts. As the term 'objective' is therefore not appropriate when speaking of care poverty, neither is 'subjective'.

But how about the term 'relative'? In poverty research, the concept of *relative poverty* is one of the most widely used approaches to analysing material deprivation. Townsend (1979, p. 915) connected poverty to the concept of *relative deprivation*, which is when people are deprived of the conditions of life that ordinarily define membership in a society. The concepts of relative deprivation and relative poverty have given rise to a large and influential research strand that understands people to be in poverty when they lack certain commodities common to the society in which they live (Hagenaars & De Vos, 1988, p. 215). In the relative poverty approach, poverty is thus defined in relation to general consumption patterns and the general income level of each society.

Over the past several decades, the concept of relative poverty has become very widely used—especially in the Global North, where the basic needs of the population are usually satisfied (e.g., Brady, 2005; Rosenfeld, 2010). In this approach, the level of material resources accessed by an individual or family is compared not to some minimum subsistence threshold, but to the resources of other people in the same society. Typically, poverty lines are defined as 50–60% of the general median income level. This notion has served to highlight the persistence of inequality within wealthy societies, in particular (Wolff, 2015).

Yet it is difficult, if not impossible, to fully follow the methodological approach of relative poverty in the study of care needs. In poverty research, the whole population serves as the reference group, but for the study of unmet care needs, it is not justified to include those who do not have care needs in the analysis. When identifying relative poverty, the resources of an individual or a family are compared to those of all others. When speaking about relative unmet care needs, however, those with unmet needs are to be compared only to those with care needs—not the general population.

Nevertheless, the term relative care poverty could maybe still fit the second measurement approach, where older people are asked whether they receive sufficient care. The reason why no global poverty threshold is used in relative poverty measurements is due to understanding the importance of the social and economic environment for poverty. Measurements are done within each society, and the poverty threshold varies across countries. When it comes to care, measurements are always based on interpretation, but these interpretations are done within the cultural context of each society. What is understood as sufficient vs. insufficient care depends on people's expectations. In turn, their expectations depend on the values and norms prevalent in the nation. Because the second measurement approach is based on self-reporting that is necessarily related to the national context, it is open to these contextual factors.

The second measurement approach is thus relative in nature, which also means that the actual situations of people who self-report (or are proxy-reported) as having their care needs unmet may be different across countries. This is a feature of the measurement approach, and it recalls the case of relative poverty, where the poverty threshold always depends on the national context. Although the second approach to measuring unmet long-term care needs is not fully identical to the one of relative poverty, there are distinctive similarities between them. It is thus called the relative approach here, while phenomenon that it identifies is called *relative care poverty*.

Conclusions

The framework for the analysis of care poverty is structured according to two dimensions. On the one hand, it is built on three domains of care needs and thus of care poverty: personal care poverty, practical care

Table 3.1 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

poverty, and socio-emotional care poverty. On the other hand, these domains cut across two different ways to measure care poverty: the absolute approach and the relative approach. When cross-tabulated, these two dimensions produce six different categories of care poverty (Table 3.1).

The absolute approach can be used in any care poverty domain to measure personal, practical, and socio-emotional care needs that are fully unmet to indicate absolute personal, practical, and socio-emotional care poverty. The same goes for the relative approach: based on self-reporting from older people (and the views of proxy respondents), insufficient support can be identified in any domain to document relative personal, practical, and socio-emotional care poverty.

In the following chapters, this framework guides the inventory of findings from existing research into unmet care needs. It aims to make the range of methodological and conceptual choices found in this body of work more manageable. The framework thus sums up the state of the art of current knowledge on care poverty in terms of its rates (Chap. 4), factors (Chap. 5), and consequences (Chap. 6).

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