

Non-take-up of social support: how do bureaucratic barriers inhibit the help-seeking process of nonprofessional caregivers? Results from a qualitative study in the Dutch municipality of The Hague.

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Editorial note: this is one of the chapters of my dissertation, and is still work in progress.

Abstract

This study seeks to understand how bureaucratic barriers inhibit the help-seeking process of nonprofessional caregivers, who are eligible for social support from social service providers in the third sector. Current literature pays insufficient attention to the role and impact of these barriers on caregiver's help-seeking behavior. To address this gap in our knowledge, this study introduces and applies the concept of *administrative burdens* from the public administration literature. Applying a qualitative research design, the perceptions and experiences of hard-to-reach caregivers are collected, described and analyzed, in order to gain an understanding of how administrative burdens lead to non-take-up of social support. Empirical data is collected from focus groups (semi-structured interview format) with caregivers in the Dutch municipality of The Hague (500.000+ inhabitants). The focus groups consist of caregivers, respectively of Dutch, Surinam, Turkish, Moroccan, The Netherlands Antilles & Aruba, and Chinese socio-cultural backgrounds. The empirical results of this study have important implications for (the future application of) the theoretical concept of administrative burdens in the context of help-seeking for social support.

Key words: *welfare state reforms, administrative burdens, non-take-up, social support, nonprofessional caregivers, third sector organizations*

1. INTRODUCTION¹

An elderly Dutch woman, who takes care of her husband, suddenly becomes ill herself, but is reticent to ask for help from a local organization. A nonprofessional caregiver from the Chinese community, who does not utilize a free service for administrative support. A young Surinam caregiver, who looks after his father, is overburdened and is in need of some support, yet he is unaware of help sources in the neighbourhood. These are all three examples of nonprofessional caregivers (individual type II in our study), who, under different circumstances and for different reasons, do not take-up social support services that are being offered by third sector organizations. This *non-take-up of social support* (Reijnders, Schalk & Steen, 2018) is highly problematic. As many studies emphasize, nonprofessional caregivers who provide care and support to someone in their social network, often find this caring relationship (very) intensive and difficult to combine with other (social) responsibilities (see e.g., SCP, 2019). They are prone to fatigue, burnout and a decline in their own physical and mental health (see e.g., Williams, 2017; Metzelthin *et al.*, 2017; Boer *et al.*, 2009; Struijs, 2006; Scharlach & Frenzel, 1986). Furthermore, it is not uncommon that caregivers simultaneously have to cope with certain physical and/or mental disabilities of their own (Murphy *et al.*, 2006) and that no one from their social network can temporarily take over and relieve them of their caring responsibilities (Cannuscio *et al.*, 2004).

Hence, to support caregivers, numerous forms of social support for nonprofessional caregivers are developed and offered by third sector organizations. These services are intended to prevent them from becoming overburdened and to strengthen and/or sustain their caregiving capacities. Yet various international studies consistently report that such services are (severely) underutilized by eligible caregivers (see e.g., Stephan *et al.*, 2018; Neville *et al.*, 2015; Brandao, Ribero & Martin, 2016; Montoro-Rodriguez, 2003; Zarit *et al.*, 1993). The situation in The Netherlands forms no exception. Almost six out of ten Dutch caregivers have unfulfilled help needs but do not ask for social support, according to a recent study (SCP, 2017). This corroborates findings from previous studies (Van Exel, De Graaf & Brouwer, 2008; Struijs, 2006), whereby even amongst substantially strained caregivers low levels of support utilization have been reported (Van Exel *et al.*, 2006). At the same time,

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however, there is ample evidence of Dutch nonprofessional caregivers being overburdened (see e.g., Van der Heide, Van den Buuse & Francke, 2018; De Klerk *et al.*, 2017). Definitions and statistics vary, but approximately one in ten (Klerk *et al.*, 2015), or one in seven (CBS, 2015) even feels heavily overburdened. In sum, there are clear and consistent signals that many caregivers have unfulfilled help needs, but that a considerable part of this population does not ask for support.

Our understanding of this non-take-up of social support by caregivers is still limited. This is highly problematic, as a failure to understand and effectively address this non-take-up poses a threat to the efficacy of contemporary social policies. There is also the risk of a “double boomerang effect” (Van Exel, De Graaf & Brouwer, 2008): when help needs remain unattended to, nonprofessional caregivers themselves, as well as the person they provide care for, may both become dependent on care and support – which would increase public welfare spending in the long run. In particular, there is insufficient systematic analysis of the role and impact of bureaucratic factors on the help-seeking process of caregivers. In the literature, bureaucratic factors are only mentioned very generically, or not even recognized as such – let alone systematically analyzed. If these obstacles to service use are better understood, they may then be addressed (more) effectively. This may then *decrease* the negative impact of administrative burdens on help-seeking by caregivers. Conversely, it is likely to *increase* their take-up of social services, meaning that more social needs are attended to, which will most likely save welfare costs in the long run.

To address this gap in our knowledge, this study applies the theoretical concept of *administrative burdens* from the public administration literature (Moynihan, Herd & Harvey, 2015). Administrative burdens consist of different costs imposed on citizens when seeking services or welfare benefits from public organizations, i.e. governmental bureaucracies. Moynihan, Herd & Harvey (2015) discern three broad categories of costs: *learning costs* (individuals must learn about the program, whether they are eligible, the nature of benefits, and how to access services), *psychological costs* (individuals face stigma of participating in an unpopular program, as well as the loss of autonomy and increase in stress arising from program processes) and *compliance costs* (individuals must complete applications and reenrollments, provide documentation of their standing, and avoid or respond to

discretionary demands). Public administration research shows that administrative burdens negatively affect the take-up of welfare benefits and social programs such as Medicaid, Social Security and food stamp programs (Moynihan, Herd & Harvey, 2015). This non-take-up is not seldom to the detriment of subgroups that are already administratively disadvantaged (Brodkin & Majmundar, 2010). This study further builds on this existing knowledge of administrative burdens in citizen-state interactions and explores the impact of administrative burdens in a different context, namely that of help-seeking for social support from third sector organizations. It is asked: *how do administrative burdens impact the help-seeking process of nonprofessional caregivers, who are eligible for social support from third sector service providers?*

A qualitative approach is adopted to gain an understanding of the administrative burdens that caregivers perceive and experience in their daily lives, which lead to the non-take-up of social support services. Empirical data is collected from focus groups (guided by a semi-structured interview format) with caregivers in the Dutch municipality of The Hague. However, caregivers who are eligible for, yet do not utilize social support services constitute a “hidden or hard-to-reach population” (Shaghaghi, Bhopal & Sheikh, 2011), especially those with non-Dutch backgrounds. Hence, to find and recruit participants for the focus groups, a collaboration with *PEP Den Haag* was established. This is an independent, local foundation that is able to reach out to caregivers of different socio-cultural backgrounds.² A total of seven focus groups were organized with caregivers, respectively of Dutch (two groups), Surinam, Turkish, Moroccan, The Netherlands Antilles & Aruba, and Chinese backgrounds.

2. BUREAUCRATIC BARRIERS IN THE HELP-SEEKING PROCESS OF CAREGIVERS

This section first takes stock of the relevant literature on (non-)help-seeking behavior of nonprofessional caregivers. Thereafter, the theoretical concept of administrative burdens (and its relevance) will be explained, which provides the means to systematically analyze how bureaucratic barriers affect the help-seeking process of caregivers.

² The term “socio-cultural background” is preferred in this study, instead of the term “race”, which is used elsewhere in the literature on nonprofessional care (see e.g., Wolff *et al.*, 2018; Peek, Coward & Peek, 2000; Burton *et al.*, 1995; Twigg & Atkin, 1994).

Literature review

In general, research on help-seeking for social support by caregivers is still limited – especially compared to research on help-seeking in other subfields, such as help-seeking for professional medical services and mental health services (see e.g., Dingwall, 2017; Pescosolido, Boyer & Medina, 2013; Rickwood & Thomas, 2012; Scheid & Brown, 2009; Andersen, 2008; Biddle *et al.*, 2007; Cauce *et al.*, 2002; Bandura, 1998). More in particular, no systematic attention is paid to the role and impact of bureaucratic barriers on the help-seeking process of caregivers. Given the emphasis policymakers place on nonprofessional care for the sustainability of welfare state arrangements (see e.g., Courtin, Jemai & Mossialos, 2014; Koopmanschap *et al.*, 2004), and given the oft-cited (increasing) importance of nonprofessional care in evolving societies (see e.g., Metzelthin *et al.*, 2017; Reijnders & Truijens, 2015; Bracke, Christiaens & Wauterickx, 2008; Van Houtven & Norton, 2004; Mant *et al.*, 2000; Twigg, 1989), this lack of interest is remarkable.

One possible explanation of this lack of systematic attention is that bureaucratic barriers simply do not exist, or have a negligible impact on the take-up of social services from third sector providers. However, this is highly unlikely – if not simply untrue. Although reliable records of actual service use from third sector providers is lacking (see also De Klerk *et al.*, 2019; Pommer *et al.*, 2018), there are some indications that bureaucratic factors indeed (severely) limit, hamper or obstruct nonprofessional caregivers from accessing and utilizing social services. In their systematic literature review, Greenwood *et al.* (2015) enumerate various “barriers potentially affecting carers from any ethnic group”, namely: “costs; availability of services (e.g. timing and funding restrictions); low awareness or lack of information about services; administration, e.g. bureaucracy, paperwork, communication with service and waiting lists; lack of transport to service; and language barriers” (Greenwood *et al.*, 2015: p. 70-71). These barriers are all subsumed under the generic label of “practical barriers” by the authors. Secondly, in another recent literature review, O’Shea *et al.* (2017) sum up various barriers for what they generally refer to as “the (timely) access to services”, namely: poor availability of appropriate services (also in case of emergency services); difficulties for caregivers to navigate the complex healthcare system; costs; and a lack of transportation services.

Notwithstanding these signals, there are three important shortcomings in the current literature: 1) it lacks the right conceptual tools to attain a more systematic understanding of bureaucratic barriers and how they affect help-seeking; 2) it neglects several important aspects of the help-seeking process; which lead to 3) rather obfuscated recommendations, complicating the design and implementation of measures to mitigate the impact of bureaucratic barriers. Regarding the first shortcoming, although some studies are cognizant of bureaucratic factors as inhibitors of service use, a more nuanced analysis of such factors is still lacking. Typically, studies that do report on obstacles for help-seeking (like the two literature reviews mentioned above) sum up different types of factors, including bureaucratic factors, and subsume these under generic – and rather meaningless – categories. A more detailed analysis of such bureaucratic factors is omitted, unfortunately. This is due to a lack of conceptual tools that allow for a more in-depth analysis of those bureaucratic factors.

Secondly, not all relevant aspects of help-seeking are taken into account in the current literature. The majority of studies fails to include non-seekers, caregivers that have quit using support services, and/or caregivers of minority ethnic groups. Furthermore, service use is mostly described in terms of *realized* access, while the preceding *process* of navigating the system of social service delivery, of gaining access, and the potential hurdles along the way, is largely neglected. For instance, often no differentiation is made between different types of bureaucratic barriers in various stages of the help-seeking process, which inhibits an understanding of when and how specific factors may lead to non-take-up or withdrawal from social services. Moreover, bureaucratic barriers to help-seeking are often considered in a rather reductionist way, in terms of ‘practical barriers’, ‘services being unavailable’ or ‘unawareness of services’, paying only scant attention to the psychological dimensions of such barriers.

More generally, there is a rather isolated focus on the individual caregiver, while many studies neglect the broader context in which the caregiver finds him-/herself. This is problematic both from an empirical and a normative stance. Empirically, external players, such as service providers, may also have an impact on the help-seeking process and should therefore be included in the analysis as well. From a more normative perspective, omitting

other external actors is problematic, as this suggests that individuals themselves bear the sole responsibility to seek support for their personal welfare problems. This is a too narrow conception, as other external actors also shape and influence the environment in which the help-seeking process is located (*cf.* Munson *et al.*, 2012; Pescosolido, in: Pescosolido *et al.*, 2011; Van Oorschot, 1995). Overall, more “holistic research” (see Groeneveld *et al.*, 2015) of external barriers and their impact on the help-seeking process is required.

Lastly, the third shortcoming of the current literature: in terms of prescriptive research, suggestions and recommendations to mitigate the impact of bureaucratic factors and to improve service supply and accessibility are often absent or remain very vague. For instance, in the study by O’Connell *et al.* (2012) caregivers complain about “bureaucracy” negatively affecting service use. The authors recommend to “improve administration, bureaucracy and communication” (2012: p. 116). However, they neither provide a clear conceptualization of any these terms – what exactly does the term ‘bureaucracy’ entail, other than a *Schimpfwort* (*cf.* Merton, 1940) used by caregivers?) – nor are such recommendations tangible enough to address the problems at hand. What should (policy) practitioners do with such vague advice? Probably different measures would be required if caregivers’ unawareness of service supply is caused by a general lack of information, as opposed to when this unawareness is due to language barriers. This, however, remains unclear in such generic advice. Prescription is easier said than done. An important first step towards better prescription is a better theoretical and empirical understanding of the bureaucratic factors at play, which could then serve as a more solid foundation for recommendations to (policy) practitioners.

In light of the above discussion, it is both necessary and relevant to conduct a more in-depth study into how bureaucratic factors affect help-seeking behavior. The next paragraph therefore presents the theoretical concept of *administrative burdens* from the public administration literature. This concept captures different types of ‘bureaucratic hassles’, onerous rules and procedures, and other negative bureaucratic factors that caregivers (may) encounter in their daily lives. It allows for a better understanding of how these shape their experiences of service delivery by third sector organizations. This concept is expected to produce useful insights for (policy) practitioners to further improve the current system of social service delivery.

What are administrative burdens and why do they matter?

In the public administration literature, the concept of administrative burdens has been applied in the context of *citizen-state interactions*, to better understand how such burdens shape and impact citizen encounters with *public* bureaucracies (see Jilke, Van Dooren & Rys, 2018; Heinrich, 2018; Moynihan, Herd & Rigby, 2016; Moynihan, Herd & Harvey, 2015; Herd *et al.*, 2013). Administrative burdens are defined as “an individual’s experience of policy implementation as onerous” (Burden *et al.*, 2012: p. 742). Three key components of administrative burdens are to be distinguished, namely: learning costs, psychological costs, and compliance costs. Although these components of administrative burdens are framed in terms of ‘costs’, this should not be interpreted as a rational approach of individuals weighing costs against expected gains to maximize their utility – which is the dominant view in non-take-up studies (see Chareyron & Domingues, 2016; but for a critical discussion of this view, see Van Oorschot, 1998, as well as chapter 2 of this thesis). Moynihan, Herd & Harvey formulate an alternative view by assuming that “the impact of burdens depends upon how individuals construe the world, not on objective measures of costs and benefits. This construal is shaped by contextual factors that frame burdens and interact with individual psychological processes, including cognitive biases that may generate disproportionate response to burden” (2015: 4). Table 7.1 below contains the different categories of costs.

Type of costs	Application to social policy
Learning costs	Individuals must learn about the program, whether they are eligible, the nature of benefits, and how to access services.
Psychological costs	Individuals face stigma of participating in an unpopular program, as well as the loss of autonomy and increase in stress arising from program processes.
Compliance costs	Individuals must complete applications and reenrollments, provide documentation of their standing, and avoid or respond to discretionary demands.

Table 7.1: The three key components of administrative burdens (Moynihan, Herd & Harvey, 2015: p. 4)

Note that administrative burdens are different from red tape. Red tape is primarily about how rules affect the experience of administrative employees within an organizational context, whereas administrative burdens pertain to the subjective experiences of citizens in their interaction with the state (see Moynihan, Herd & Harvey, 2015; Heinrich, 2015).

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Administrative burdens can manifest themselves in “any context in which the state regulates private behavior or structures how individuals seek public services” (Moynihan, Herd & Harvey, 2015: p. 2). Additionally, red tape is, by definition, about rules that do not serve any legitimate purpose (Bozeman, 2000), while administrative burdens “will often serve legitimate purposes and are not inherently bad” (Moynihan, Herd & Harvey, 2015: p. 5, footnote). A final distinction between administrative burdens and red tape is that the former consists of supplementary components, other than the compliance burden of red tape (Moynihan, Herd & Harvey, 2015).

Moreover, administrative burdens in citizen-state interactions matter. Whereas theoretical and empirical studies are predominantly U.S.-oriented (with a few notable exceptions, such as Heinrich, 2015), there is compelling evidence of the negative effect of administrative burdens on the take-up rates of various types of welfare programs and social security benefits. A general finding in this line of research is that non-take-up rates by eligible beneficiaries of means-tested programs are much higher compared to universal programs (see e.g. Herd, 2015; Van Oorschot, 1998). For a number of public welfare programs in the U.S., Moynihan, Herd & Harvey (2015) report (sometimes drastically) lower take-up rates for a range of means-tested benefits, compared to universal programs like Social Security and Medicare. In the latter case, take-up rates are near 100%, while take-up rates for various means-tested programs are the following:

“40%–60% for Supplemental Social Insurance (Elder and Powers, 2006); two-thirds for the Supplemental Nutrition Assistance Program (SNAP, frequently referred to as food stamps) (Food and Nutrition Service, 2007); 30%–60% of unemployment insurance benefits (Kroft, 2008); 50%–70% for Medicaid (Sommers et al., 2012); and 75% for the Earned Income Tax Credit (EITC) (Plueger, 2009). Although Aid to Families with Dependent Children (AFDC) had an estimated take-up rate of between 77%–86%, participation rates declined dramatically after 1990s welfare reform, so that its successor, Temporary Assistance for Needy Families (TANF) had a much lower take-up rate of between 42 to 52% (ASPE 2007, II-19)” (Moynihan, Herd & Harvey, 2015: p. 6).

And, *vice versa*, Herd *et al.* (2013) show how the *reduction* of administrative burdens significantly *increased* take-up of Medicaid services in the state of Wisconsin. This was the result of an extensive reform program that shifted – through various measures, including auto-enrollment and program and form simplification – administrative burdens from citizens

to the state. It demonstrates how administrative burdens matter for enrollment for Medicaid services and how “relatively simple administrative changes can reduce burden, resulting in positive and substantive increases on enrollment” (Herd *et al.*, 2013: p. 577). Based on the outcome of the above studies, some argue to change program enrollment procedures from self-application to assistance with program enrollment, or even to auto-enrollment procedures (no action required from the beneficiary), in order to increase take-up rates and ameliorate the effectiveness of welfare programs (see Moynihan, Herd & Harvey, 2015).

From a normative point of view, these findings on non-take-up raise important questions about the accessibility, distributive justice and (in)equality in relation to the design, implementation and effects of social policies and welfare programs. These studies ‘uncover’ how seemingly technocratic rules, procedures, administrative structures, and other policy measures, are in fact inherently political. The way they are designed and implemented carry real consequences for potential welfare recipients. Administrative burdens may restrict welfare recipients in fully exercising their social rights. They are therefore considered as the product of ‘politics in disguise’, or as Moynihan, Herd and Harvey (2015: p.2) put it:

“(…) administrative burdens form an important part of the “hidden politics” that characterize contemporary battles about the role of the state (Hacker 2004; Thompson 2012). Policymakers will alter burdens as an alternative or complement to more overt forms of political activity. The attractiveness of administrative burdens as a form a “policymaking by other means” (Lineberry 1977) is tied to their opacity. The details of administration that give rise to burden may be largely invisible to the public and even most policymakers, their impact poorly understood. Changes to burdens may be presented as technical fixes without any specific policy intent, or to serve values widely supported or perceived as apolitical (Edelman 1985).”

As all preceding examples illustrate, the concept of administrative burdens has been applied in the context of citizen-state interactions, or the “bureaucratic encounters” (Kahn *et al.*, 1976) between citizens and *public* organizations. It has not (yet) been applied in the context of help-seeking for social support services from third sector organizations. However, administrative burdens may also thwart access to and utilization of support provisions from third sector organizations (*cf.* Sannen, 2003). In other words, caregivers’ (non-)help-seeking for social support from third sector providers highlights this as a suitable context for research on administrative burdens.

Summary

This study extends public administration research on administrative burdens to the context of help-seeking for social support by nonprofessional caregivers. The analysis of the role and impact of bureaucratic factors on help-seeking for social support will be based on the different components of administrative burdens: learning costs, psychological costs and compliance costs. This theoretical concept is useful, as it unifies different types of administrative costs that nonprofessional caregivers may encounter in their help-seeking process. This allows for a more detailed investigation of administrative burdens in the interaction between third sector organizations and potential recipients of social support services, i.e. nonprofessional caregivers.

3. EMPIRICAL CONTEXT AND RESEARCH DESIGN

This section describes the empirical context of this study. It provides key statistics about nonprofessional care and describes the main features of the local social service system of the Dutch municipality of The Hague. Subsequently, the research design is presented, which further elaborates on the qualitative approach that is adopted to investigate the influence of bureaucratic factors on help-seeking for social support. This section concludes with a description of the process of data collection and data analysis.

Nonprofessional caregiving and social support services in The Hague

The Hague has 533.026 inhabitants and is the third largest city of The Netherlands. Like other Dutch municipalities, The Hague has formulated policy criteria to determine whether an individual can be officially labeled as a nonprofessional caregiver. These policy criteria are that an individual must take care of someone from within their own social network (family member, friend, neighbor) for at least eight hours a week, or for three consecutive months (Gemeente Den Haag, 2018a). Caregivers may perform all sorts of primary and/or secondary tasks, whereby the former refers to caring tasks and the latter to other, 'indirect' tasks, such as administrative work, cleaning the house and doing groceries. Accurate, longitudinal statistics are lacking, but estimations of the number of nonprofessional caregivers hover somewhere between 50.000 (Mantelzorgakkoord, 2009), 79.000 (Gemeente Den Haag, 2013; Beneken Genaamd Kolmer, 2011), 86.000 (Werk en Mantelzorg, 2015) and 94.000

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(Den Haag mantelzorg, n.d.). A citizen survey of 2015 reported that 28% of the nonprofessional caregivers provides care to their parents and/or parents-in-law, 23% to other nuclear family members, 15% to other extended family members, 16% to friends or acquaintances, and 15% to someone in the neighborhood (Dimensus, 2015).

Like in The Netherlands as a whole (and in other countries as well, for that matter), in The Hague there are clear signals of considerable numbers of caregivers being (severely) overburdened. Even though exact numbers are lacking, but different sources estimate that somewhere around 12.000 (Beneken Genaamd Kolmer, 2011) and 16.000 (Mantelzorgakkoord, 2009) caregivers in The Hague are severely strained or overburdened. This is why specific social support provisions are developed, intended to prevent them from becoming overburdened and to strengthen and/or sustain their caregiving capacities. An estimated total of over four thousand third sector organizations in The Hague offer social support services for caregivers who are in need of help (Gemeente Den Haag, 2018b). Local policymakers, emphasizing individual responsibility to take care of personal welfare problems, expect caregivers who are in need of social support to turn to these third sector organizations first, before seeking other, more expensive forms of (publicly funded) support. Examples of such third sector organizations are care hotels, voluntary associations, religious institutions, home care organizations, online support platforms, social welfare organizations, day/night care facilities, co-operatives, and community centers. These organizations (greatly) vary in terms of geographical presence; organizational configuration; budget; clientele; level of specialization; and service supply.

Some are spread out all over the city and are present in all neighborhoods, while others only operate in specific areas of the city. Some may have many physical locations, while others may only be found online. Some are big and cater to many individuals with many different welfare problems, while others remain relatively small and provide more specialist services. Some offer highly specific services, such as emotional support for young nonprofessional caregivers who are (or run the risk of becoming) overburdened. This while other organizations offer very generic provisions, which are intended for a much larger target group, such as practical household services (cleaning services, maintenance work, gardening, etc.) or administrative support (e.g. filling out tax forms). For analytical purposes, this study

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distinguishes between four types of social support: instrumental support, companionship, personal care, and emotional/psychological support (cf. Reijnders, Schalk & Steen, 2018). Table 7.2 below provides some concrete examples of support services for caregivers, which are offered by third sector organizations in The Hague.³

		Examples of social support services offered by third sector organizations in The Hague
Content of social support	Instrumental	Administrative help filling out tax forms with the help from a local community center that offers financial support
	Companionship	A bi-weekly social activity with a buddy from a local voluntary agency
	Personal care	A home care organization offering help to take medication
	Emotional/psychological	An Alzheimer café where overburdened caregivers can meet and may receive emotional support from their peers (<i>lotgenotencontact</i> in Dutch)

Table 7.2: Social support provisions for caregivers from third sector organizations

Signs of non-take-up in The Hague

Despite the wide range of services being offered to caregivers, non-take-up of social support services also occurs in The Hague. Although accurate city-level data are unavailable, a few reports indicate that a considerable number of eligible caregivers does not ask for social support. It is estimated that around 25% of strained caregivers had unfulfilled help needs (Gemeente Den Haag, 2018c). It was also reported that up to 70% of eligible caregivers was unaware of the existence of support services (Gemeente Den Haag, 2012b). *Vice versa*, third sector organizations do not reach all caregivers. In 2009 only 5% of caregivers was ‘in the picture’ (Mantelzorgakkoord, 2009). Over the years this did not seem to improve much, as in 2016 a special taskforce still aimed to reach 1.700 caregivers per year, which is still only a fraction of the population of (severely overburdened) caregivers – let alone the total population of caregivers. And a recent study of the use and user friendliness of a special website about social services for caregivers (www.denhaagmantelzorg.nl) concluded that online information could and should be improved, as caregivers were not really consulting

³ Information about such organizations and their services can also be found online at, e.g., <https://denhaagmantelzorg.nl/home> (information about nonprofessional care), <http://www.respijtwijzerdenhaag.nl/> (information about respite care for nonprofessional caregivers), and <https://www.socialekaartdenhaag.nl/> (the ‘social map’ of The Hague).

that website (PEP Den Haag, 2016). One example to further illustrate this: there is a compensation in kind for caregivers (the so-called *mantelzorgwaardering* in Dutch) that can be used to obtain all kinds of products and services from that website. This benefit is restricted to one nonprofessional caregiver per patient, who must be an inhabitant of the municipality of The Hague, and self-application online is required. Due to a lack of knowledge and a rather complex website, many caregivers do not consult this website, leading to non-take-up of this specific benefit.

Other, more anecdotal evidence of non-take-up stems from a group of local experts, who, based on their professional experience, perceive several bottlenecks regarding access to respite care services (PEP Den Haag, 2017). They refer to the existence of waiting lists and caregivers experiencing difficulties to navigate the supply of services and to find suitable support services. They indicate that caregivers are unaware of (being eligible for) certain support services and benefits, that they have difficulties to apply for them, or that they encounter other types of barriers to service use. However, this is only one example. A more in-depth analysis of the underlying mechanisms and processes of such bureaucratic barriers is still lacking. Hence, this study aims to fill this lacuna in our knowledge. The next paragraph presents its research design and explains *how* the investigation will be conducted.

Research design

A qualitative approach is adopted to gain an understanding of the perceptions and lived experiences of caregivers who are eligible for social support, yet refrain from asking for that support. However, caregivers who have (multiple) latent help needs but do not utilize social support services, constitute a “hidden or hard-to-reach population” (Reijnders, Schalk & Steen, 2017; Shaghghi, Bhopal & Sheikh, 2011). That is, there is no register of caregivers with (multiple) latent help needs from which to draw representative samples, which is much *unlike* research on non-take-up of social security benefits that may draw from administrative databases of eligible welfare clients (see e.g., Van Oorschot, 1998). Neither is there an overview of social service utilization from third sector providers, as a systematic, central registration of service use is lacking (see also Pommer *et al.*, 2018). This implies that sampling and recruiting respondents is not a straightforward affair. And to further complicate matters: caregivers of ethnic minority groups are even harder to reach, which is

also why they are underrepresented in research on nonprofessional care (see Greenwood *et al.*, 2015; De Klerk *et al.*, 2015; Den Haag OIV, 2011; Forum, 2011). In all, given the complexity of the research problem and the challenge of finding and recruiting respondents, qualitative methods are favored over quantitative methods in this study (*cf.* Groeneveld *et al.*, 2015). Empirical data is collected from focus groups with caregivers. Focus groups are appropriate for more exploratory forms of research (Stalmeijer *et al.*, 2014), to gain a better understanding of a poorly understood or ill-defined topic (see also Kitzinger, 1995). Secondly, the focus group is a technique that is particularly sensitive to cultural factors and is often used in cross cultural research (Kitzinger, 1995), which is another reason why this technique is considered useful for current research purposes.

To locate and recruit participants from this hard-to-reach group of caregivers, it was decided to collaborate with local experts, who could act as intermediaries (see also Stephan *et al.*, 2018; Tonkens, Van den Broeke & Hoijsink, 2008; Morgan *et al.*, 2002; Groger, Maybarry & Straker, 1999). Using intermediaries to gain access to hard-to-reach populations is not uncommon, see for instance a study on social exclusion (Van Bergen & Gillissen, 2015) and a study of young adults with criminal records (Zand-Kurtovic, 2017). In this case, a collaboration with *PEP Den Haag* was established. This is an independent foundation that provides guidance and advice to caregivers. This organization employs social workers of various socio-cultural backgrounds, who are in contact with (or are able to get in touch with) caregivers from different ethnic groups. So, through their contacts, caregivers were recruited for the focus groups. Caregivers received a free lunch in exchange for their participation (some form of compensation for participation is quite customary in focus group research, see e.g., Scharlach *et al.*, 2006; Morgan *et al.*, 2002; Morgan, 1997).

Furthermore, the focus groups were “segmented” (Morgan, 1996), based on the socio-cultural background of the participants. A total of seven focus groups were organized with caregivers, who respectively have a Dutch (two groups), Surinam, Turkish, Moroccan, The Netherlands Antilles & Aruba, and Chinese background. Each group consisted of 4-9 participants (*cf.* Stephan *et al.*, 2018), with a total of 40 participants. The Dutch, Surinam, The Netherlands Antilles & Aruban, and Chinese groups were a mix of male and female caregivers. The Turkish and Moroccan groups were respectively only male and only female

groups. The vast majority of focus group participants has quite a 'career' as a caregiver, with at least several years of caregiving experience, going up to 10+ years of experience, and even up to 27 years (in the case of a caregiver who takes care of her autistic son). Most care recipients live at home, a few stay in a care institution (e.g., a nursing home) and are visited regularly by their caregiver.

Segmentation of the focus groups offers two advantages. Firstly, it builds in a comparative dimension, allowing to investigate similarities and differences between groups (Morgan, 1996). A systematic literature review found that only "few studies compared minority ethnic carers' perceptions with majority ethnic groups, making it difficult to identify issues specific to minority groups" (Greenwood *et al.*, 2015). Hence, by interviewing nonprofessional caregivers of different social-cultural backgrounds, one can compare differences and similarities of their perceptions and experiences. A second advantage of segmentation is that it facilitates focus group discussions, as participants are more similar to each other (Morgan, 1996). The latter aspect, the homogeneous composition of focus groups, is recommended by most researchers (see also Kitzinger, 1995; Hughes & DuMont, 1993). In this case, there is an additional reason to structure the focus groups in this way, because of language similarities. Participants feel more comfortable when they can express their opinions, feelings and emotions in their native language (Scharlach *et al.*, 2006; Merton, Fiske & Kendall, 1956), something that was also affirmed by social workers of *PEP Den Haag*.

Focus group interviews and data analysis

Each focus group meeting took place in the building of *PEP Den Haag*, a central location in the city. Participants were briefed about the nature of the focus group beforehand. In this briefing they were also informed that their personal data would not be shared with other parties and that all research output would be anonymized. And it was emphasized that there were no 'right or wrong answers', meaning that all participants were invited to share their personal views on caregiving and support services in an open way. It was guaranteed that participating in this study did not have any consequences for their social rights whatsoever. Furthermore, each focus group was accompanied by a social worker from *PEP Den Haag*. In case of the non-Dutch speaking groups, the social worker also acted as translator. A semi-structured interview guide was developed to guide focus group conversations, containing a

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variety of topics, based on the concepts derived from the literature (Morgan *et al.*, 2002; Hughes & DuMont, 1993). The same semi-structured interview script was applied to each focus group. Duration of the group conversations was 1,5 hours or more.

At the start of each focus group conversation all participants were asked to introduce themselves, to share some of their personal background, and tell more about their caregiving relation (*cf.* Hughes & DuMont, 1993). Subsequently, their knowledge and understanding of the terms nonprofessional caregiver (in Dutch: *mantelzorger*) and respite care services (in Dutch: *respijtzorg / respijtzorgvoorzieningen*) was gauged. These are common policy terms used both by policymakers and third sector providers. Furthermore, it was asked if they were aware of the existing supply of social support within the city of The Hague. And if they received (some) social support services in the past (or were still receiving it at the time), they were invited to share their experiences. It was asked how (easy or difficult) it was to find and acquire that support. Another important 'talking point' was if participants received information about available services from professionals, and particularly general practitioners (GPs), as they are considered an important point of contact for caregivers (Courtin, Jemai & Mossialos, 2014; Lamb *et al.*, 2011). It was also asked whether other sources were consulted for information (and if so: which ones and how).

When participants experienced any difficulties in the help-seeking process, their answers were further probed to find out what type of problems or barriers they perceived and/or encountered. Throughout the focus group conversations, participants were stimulated to provide examples of their (non-)help-seeking behavior and any burdens they may have encountered during that process. Finally, they were asked to provide their own ideas and suggestions – if they had any – to improve accessibility of social services in The Hague. Yet, while having prepared a set of questions beforehand, it must be emphasized that the semi-structured interview format allowed for a flexible, open-ended approach, also leaving ample room for other reasons and conditions to emerge during the focus group conversations (Morgan, 1996).

Finally, to analyze the focus group data, relevant parts of the focus groups conversations were filtered out and labelled. This produced an overview of 1) the socio-cultural

background of the focus group participants and general information about the caregiving relationship, 2) the level of knowledge regarding ‘technical policy terms’ in relation to nonprofessional care, as well as the level of knowledge about (the supply of) social support provisions that were offered by third sector organizations; 3) the subjective perceptions of and experiences with social support provisions from third sector providers; 4) the type(s) and impact of (perceived) administrative burdens in help-seeking for social support; 5) caregivers’ suggestions and advice to improve (information about) social services; and 6) other relevant themes and issues that had emerged from the focus groups inductively and were not directly related to the questions from the interview script.

4. FINDINGS

This section will first report on the findings regarding the three components of administrative burdens, respectively learning costs, psychological costs, and compliance costs. Subsequently, it will present the suggestions that were made by the focus group participants about potential improvements for (information about) social services. The last part of this section discusses the implications of this study’s findings for the theoretical concept of administrative burdens.

Administrative burdens: learning costs

The first aspect of learning costs is that potential participants must learn about the program (Moynihan, Herd & Harvey, 2015). In general, the empirical findings clearly indicate that most caregivers are unaware of existing help resources. This starts with some of the specific terminology used by (policy) practitioners in relation to nonprofessional caregiving. When asked, respondents in the Turkish, Moroccan, and Chinese groups appear to be unfamiliar with the term nonprofessional caregiver (*mantelzorger*), whereas caregivers from the Dutch, Surinam, and Netherlands Antilles & Aruba groups are (somewhat) familiar with the term. Regarding the term respite care (*respijtzorg*), most caregivers are not familiar with it, and the remainder has a wrong or limited perception of it. It was generally agreed that such technical terms are needlessly complex and confusing for caregivers. As one participant asked rhetorically: *‘Why would one start googling for respite care, if one does not even know*

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the term? In light of this, it came to no surprise that none of the respondents was aware of the website with information about services for caregivers (www.respijtwijzerdenhaag.nl).

Nevertheless, this unawareness and lack of knowledge is quite striking, given their prolonged 'careers' as caregivers, and their experience with all sorts of healthcare, social service, and governmental agencies. To illustrate: one caregiver from the Netherlands Antilles & Aruban group took care of both her parents for more than 15 years, who lived a 1,5 hours car drive away from The Hague, as well as her brother who has psychiatric problems. Obviously, this meant a lot of traveling back and forth, but it also involved managing the personal welfare plan (the so-called *persoonsgebonden budget*) to organize care and support for her parents. Another caregiver, one from the Moroccan group, was divorced, has two children, and combines her job as a cleaner with taking care of her father for more than 12 years now. Together with her two sisters, they do all sorts of household chores, administrative tasks, and help their father taking a shower. A young male Surinam caregiver helped his grandmother in paying family visits, going to the hospital, and cleaning her house, while combining this with his study. These three examples are no exception to the rest of the respondents in terms of (the variety of) tasks and responsibilities caregivers fulfill in their daily lives. These require planning and organization skills and competences, as well as knowing one's way in the social service system.

Given these abilities and experiences of these respondents, one may anticipate (much) higher levels of awareness and knowledge about services specifically targeted at them. Yet, actually the opposite was observed in the focus group discussions. It seems that the bureaucratic experience caregivers have gained over time in their dealings with all sorts of agencies does not translate into them being aware of support services that are available to them as caregivers. Linking this to Taleb's notion of the "domain specificity of our reactions"⁴ (2007: p. 53), it seems that bureaucratic competences of caregivers can be quite domain specific: many caregivers put their bureaucratic competences to good use in one domain, but not in the other domain, when it comes to organizing support for oneself. This may be

⁴ Taleb describes this as follows: "By domain-specific I mean that our reactions, our mode of thinking, our intuitions, depend on the context in which the matter is presented, what evolutionary psychologists call the "domain" of the object or the event. (...) We react to a piece of information not on its logical merit, but on the basis of which framework surrounds it, and how it registers with our social-emotional system" (2007: p. 53).

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coined as the *domain specificity of help-seeking competences*. When linking this to the subjective experience of administrative burdens, it appears these can somehow ‘overrule’ those help-seeking competences. Even though many caregivers dispose of sufficient competences, it does not necessarily mean that these are strong enough to overcome burdens or barriers they experience when it comes to organize support for themselves. It is also indicative of how the subjective experience of administrative burdens can dominate the more cognitive-rational processes in help-seeking behavior. The latter aspect – the dominance of subjective perceptions and feelings over more rational-cognitive elements in the help-seeking process – will be further elaborated upon later in the chapter, as it has important implications for the theoretical concept of administrative burdens.

In terms of information supply, it appears that professionals, such as GPs, neither provide information about, nor guide caregivers towards support services. As one Surinam caregiver succinctly put it: *“There is simply insufficient information. I never received any information, from no one.”* Although professionals, such as GP’s and social workers, are supposed to actively inform caregivers about the availability of support services, only one participant had received information from his psychiatrist, and one caregiver was forwarded to a case manager. The rest of the participants said they had not received any information from a professional. In spite of their frequent contact with various professionals and agencies, caregivers were not made aware of such support services. Moreover, the non-Dutch speaking groups also experience language barriers. Information on nonprofessional care(giving) is usually only available in Dutch – sometimes in English, but rarely in other foreign languages – and interpreters are not always available and/or are unaffordable. For instance, Chinese respondents state that language problems are an additional threshold for service use. While they have come across some information leaflets at the library and the community center, they were unable to read them.

In spite of this lack of awareness/knowledge, when we explained these terms, some caregivers – again from the Netherlands Antilles & Aruba, and the Dutch groups – were able to come up with some specific examples of such services. What they mentioned were care hotels, daycare facilities (*dagopvang*), and support from care volunteers (*zorgvrijwilligers*). *A fortiori*, a few caregivers had tried to apply for, or – though even fewer – were actually

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utilizing (some form of) social support, albeit not being aware of the 'official' terminology of those services. This was, for example, the case for a Surinam caregiver. After being informed about the official terms, she recognized that her autistic son participating in social activities through a local foundation, actually 'counted' as respite care. Up until then she was not really aware of this. Another example is that of a Surinam caregiver, who made use of a day care facility, but did not know this was formally known as respite care.

Aside from learning about programs and services, the three other aspects of learning costs were also observed, namely knowing if one is eligible to receive support, the nature of the program/service, and how services may be accessed (Moynihan, Herd & Harvey, 2015). The few respondents that did have some experience with social support from third sector providers, indicate that: 1) both online and offline, it is challenging to navigate the supply of social services; 2) once a service is found, it often remains unclear to them what exactly is being offered; and, one step further in the help-seeking process, when they wanted to apply for a service, 3) eligibility criteria and application procedures often appeared to be unclear. An example of the latter concerns a caregiver who lives in The Hague, but takes care of someone who lives in an adjacent municipality. As it turned out, certain services and benefits were unavailable to this caregiver, as the person who was taken care of was not formally an inhabitant of The Hague.

In sum, all types of learning costs, as specified by Moynihan, Herd & Harvey (2015), occur in this help-seeking context, all negatively affecting the help-seeking process. Significantly, it should be added that non-Dutch speaking caregivers face even higher learning costs due to language barriers.

Administrative burdens: psychological costs

As specified by Moynihan, Herd & Harvey (2015), psychological costs may arise from stigma associated with a specific program or service; a (perceived) loss of autonomy; and an increase in stress levels due to cumbersome organizational/program processes. Our data indicate that 1) there is variance between different focus groups in the way that 'cultural-psychological' factors impact help-seeking; 2) for some caregivers it seems psychologically easier to utilize secondary support services, compared to primary support services; and 3)

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there is a 'time sequence' of different types of psychological costs. Below, these findings will be further illustrated.

Firstly, respondents from the Turkish, Moroccan, Surinam, The Netherlands Antilles & Aruba, and Chinese groups experience specific 'cultural-psychological' costs to seeking help from third sector providers. In these focus groups, caregivers are strongly inclined to ask for support from within their personal social network. Turkish caregivers indicate that in their culture this is generally more difficult, as they are reluctant to discuss personal matters with someone outside the family, even if it is with a trusted professional like a GP. As a Turkish caregiver said: *"No, we don't do that. In the Turkish culture it is difficult to discuss such sensitive issues with your GP. You are not going to tell that you cannot take care of your own mother."* It was further added that only as a last resort, for instance in an emergency situation or if the family could not cope anymore, would they consider using external support from third sector organizations. In the Moroccan group it was remarked that: *"Asking for help is a difficult step, as it may signal that you are incapable of, or even not willing to take care of your own father and mother. Besides, they also expect us to take care of them ourselves."*

Caregivers in the other non-Dutch groups made similar statements, emphasizing that the social network, and then mostly the direct family members, is the most important source for social support. Chinese respondents also say they prefer to seek help from within their family. They are not inclined to utilize social support sources outside of the family. And, as a final example: a Surinam caregiver, belonging to a household of eleven, said that the family was the primary source for care: *"We share caring tasks amongst each other. We know each other"* (respondent used a Dutch expression: *'ons kent ons'*). These findings are in line with the few other studies that include caregivers of non-Dutch backgrounds. These also report that these caregivers strongly incline towards retaining caring responsibilities within the family (*cf.* Forum, 2011). While it is difficult to pinpoint precisely, factors like family obligation, tradition, a specific sense of pride, feelings of shame, or some kind of interplay thereof, seem to withhold non-Dutch caregivers from utilizing third sector support sources. In contrast, respondents from the Dutch focus groups did not experience such cultural-psychological barriers.

Secondly, none of the participants was familiar with the difference between primary social support (temporarily taking over caring tasks from the nonprofessional caregiver) and secondary social support services (instrumental support such as a shopping service, and administrative support such as filing taxes). This is unsurprising, given the low levels of awareness of service supply. However, once this difference was explained, some caregivers indicated that it would be easier to use secondary services, as they found it more difficult to entrust their direct caring responsibilities to third sector providers. Especially caregivers from the two Dutch groups became interested – some even enthusiastic – of the possibility to use secondary services. Such services could be useful for them, as they were hesitant to burden anyone from their personal social network with such tasks. Notwithstanding this positive attitude, an important condition for them was that it should not be too complicated to arrange this help (in more specific terms: learning and compliance costs should be low), otherwise they would not do it. Still, at least for some caregivers, it seems psychologically less burdensome to use certain secondary services from third sector providers, compared to – even temporarily – handing over their primary caring tasks. This can be linked to a finding in other studies on social support, namely that individuals find it difficult to, or refrain entirely from asking for help for what they feel to be personal or intimate help needs (Vreugdenhil, 2012; Linders, 2010).

Thirdly, although the current conceptualization of administrative burdens does not specify any ‘time sequence’ of different types of psychological costs, this study does find some indications thereof. The empirical findings hints at three different types of *ex ante* psychological costs, as well as psychological costs that may occur in later stages of the help-seeking process. One clear example of *ex ante* psychological costs is that caregivers are hesitant to (temporarily) hand over some of their responsibilities to someone from an external organization. Caregivers feel a strong moral responsibility for the one they take care of, so this is not an easy decision to make and incurs psychological costs. This feeling of moral obligation and a reluctance to hand over their responsibilities to ‘strangers’ was common to all respondents. Furthermore, two other forms of *ex ante* psychological costs in some caregiver groups were observed, namely 1) the perception that it would be difficult to receive (more) social support, and 2) a general distrust in organizations.

Regarding the first, while caregivers in other groups also doubt whether it would be easy to ask for support from external organizations, this feeling was most pronounced in the Dutch groups. These caregivers generally find the social service system to be complex and non-transparent. In addition to this, for many of them negative past encounters with all sorts of healthcare, welfare and government organizations make them to refrain, or at least hesitant to engage with any organizations to ask for (additional) help, including third sector organizations. Many have experienced what they consider to be 'bureaucratic hassles', or the – in their eyes – superfluous rules, regulations, forms, and procedures they encounter when organizing care and support for the ones they are looking after. Such experiences shape their perceptions and negatively affect their willingness to ask for help. Hence, negative past encounters cast their shadow onto future behavior. As said, however, while this was most visible in the Dutch groups, this perception was also present in other groups. As a Surinam caregiver, for instance, remarked: *"After a couple of bad experiences with organizations, you just want to keep matters in your own hands as much as possible."*

Regarding the last *ex ante* psychological cost, a general distrust in organizations was noticeable in the group with Turkish caregivers. For them, this was another important reason not to ask for help from outside the family. Still, they would turn to an external party for help, in case of an emergency situation, or if caring responsibilities could not be coped with anymore within the family. So, they do not oppose such help at all costs.

The majority of psychological costs that was observed, pertained to the earliest stage in the help-seeking process. Yet there are some examples of psychological costs occurring in later stages of the help-seeking process as well. The few respondents who found and tried to utilize resources from third sector providers, indicated that learning costs due to the complexity of service supply and the vagueness of what support services would exactly entail, also had a psychological impact. It gave them a sense of unease which also made them hesitant to ask for help. This also points to the interrelatedness of some types of learning costs and psychological costs.

Administrative burdens: compliance costs

Now for the third and final component of administrative burdens: compliance costs. These pertain to completing application forms and enrollment procedures; applicants providing documentation of their standing; applicants interacting with representatives of service providers and avoid or respond to their demands (Moynihan, Herd & Harvey, 2015). Frankly though, given the low levels of service use amongst respondents, there is not much data on this specific component. Then again, low service use is not very surprising, as the focus groups consist of hard-to-reach caregivers (and recall that low service use is no aberration even amongst the general population of caregivers, as was already mentioned in the introduction of this chapter). However, while not observing the *actual* experience of compliance costs in the application for support services for caregivers, there were quite some complaints about compliance costs caregivers encountered when they organized care and support for the ones they were looking after.

A number of caregivers in different groups managed a personal welfare plan (*persoonsgebonden budget*) and had some negative experiences in organizing care and support. To illustrate: a Moroccan caregiver was confronted with compliance costs when managing the personal welfare plan for her brother. She said it took quite the effort to get this personal welfare plan in the first place, and it also proved challenging to apply for services: *“You have to fill out a lot of paperwork and pass along private data, but then often you get to hear ‘no’, or it suddenly appears to be very difficult [to receive the necessary help].”* On the other hand, one Surinam caregiver received help from a case manager, supporting her in organizing care. She said this saved her a lot of administrative work, leaving more time to spend on other things. Nevertheless, this was one of the few exceptions. Many others had experienced (some form of) compliance costs (and learning costs, for that matter) when organizing care for someone within their social network. As another Moroccan caregiver put it: *“Usually you have to do a lot to apply for a service, such as filling out paperwork. But caregivers do not want all that hassle.”*

So, while many caregivers lacked *direct* experience of compliance costs for caregiver support services, the *perception* that such burdens would arise, the expectation of having to deal with additional burdens, appeared to negatively affect help-seeking. They want to avoid any

extra burdens, as their caregiving tasks already take up a lot of time and energy. Like we saw with the interrelation between learning costs and psychological costs, the above is also indicative of a relation between compliance costs and psychological costs. Or, in this case, it would be more accurate to speak of *expected* compliance costs that have psychological repercussions as well.

Finally, by no means do low levels of service use that were observed, render the component of compliance costs irrelevant in the context of help-seeking from third sector providers. Additional research is necessary to further look into the role and impact of compliance costs on help-seeking for social support from third sector providers. One possibility for such follow-up research could be to identify locations of third sector organizations that are visited by caregivers and to interview them about their personal experiences with service use. This way, one is expected to be more successful in assessing the presence of compliance costs and what their impact is on the help-seeking process.

Recommendations by caregivers

In the last part of each focus group session, participants were asked to share their thoughts and suggestions to improve (information about) social services. This generated a rich collection of ideas and recommendations that can be summarized as follows:

1) A common sentiment across all focus groups is that more and better information is required about the content and quality of social services for caregivers. What can they expect exactly if they would decide to use social support services from third sector providers? This corroborates findings from other studies, such as Wiles (2003), emphasizing the importance of transparency and adequate information about service quality, otherwise eligible caregivers are reluctant to utilizing certain services. For example, when caregivers are considering to temporarily hand over their caring responsibilities so that they can take a short break, they want to know that the person they take care of will be in good hands. Quite simply: if caregivers trust the service is of sufficient quality, they are more likely to use that service. In other words, transparency about what they can expect, and reassurance of sufficient quality contribute to lowering psychological costs in relation to service utilization. And when caregivers decide to use support services, the application process should be clear,

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fast and without any unnecessary paperwork. “*Caregivers do not like paperwork*”, as one Surinam caregiver concisely put it.

2) Regarding the ‘technical policy terms’ in relation to nonprofessional care, respondents urged the need to simplify terminology. For the term nonprofessional caregiver (*mantelzorger*) they could not immediately come up with a viable alternative. But with regards to support services for caregivers, and specifically for a term like respite care (*respijtzorg*), it was suggested to put it in more common and familiar terms like ‘help for caregivers’. It was believed this would increase the visibility and ‘findability’ of social support services, both on- and offline. Especially for non-Dutch (speaking) caregivers such technical terms further add to the learning costs. Participants from the Moroccan, Turkish and Chinese groups prefer to communicate in their native languages. Given the personal, rather delicate nature of the matter, they emphasize that this communication should be sensitive to their cultural norms and values. Like we saw earlier, for many caregivers it is far from self-evident to ask for support from third sector providers – let alone handing over their direct caring responsibilities for their loved ones.

3) Asked about suitable locations to inform caregivers about support services, a wide array of options was suggested. These may be divided into *usual* and more *unusual* locations. The former concerns locations like general practitioners (GPs), hospitals, municipal agencies, community centers, and public libraries. GPs were mentioned the most, as respondents already know these professionals and have a trusted relationship with their GP. Several respondents further added that information about services could be provided by support staff (specialized in nonprofessional care), this would not necessarily have to come from the person of the GP. Perhaps the more unusual sites for information are taxi and transportation services, student associations, employers (personnel department), schools, the market place (e.g. *De Haagse Markt*, one of the major market places in the city), cultural institutions, sports clubs, to be erected ‘pop-up stores’ where caregivers frequently pass by in their daily lives (at strategic locations spread across the city), and ‘culturally specific locations’ such as Chinese toko’s and restaurants, and the mosque. In addition, online information about support services should be made available in a more comprehensible (i.e. non-technical), transparent and user-friendly way. However, many participants believed that word of mouth

is by far the most effective way to spread information, not least because this would be in one's native language and/or would take into account one's cultural norms. Word of mouth would also increase the likelihood of reaching the hard-to-reach caregivers.

Administrative burdens in the help-seeking process

What are the theoretical implications of these findings? How do the empirical results inform the further development and application of the concept of administrative burdens in the context of help-seeking for social support? Three implications can be discerned, some of them were already touched upon in preceding paragraphs. These implications are: 1) a 'time-ordering' of administrative burdens within the help-seeking process; 2) an interrelationship of different types of administrative burdens and a cumulative negative effect of similar types of factors; and 3) the influence of subjective experiences and perceptions of burdens on the more rational-cognitive elements in help-seeking behavior. Regarding the first: there are indications that different types of administrative costs occur in different stages of the help-seeking process. More specifically, different types of psychological costs seem to play a role throughout the entire help-seeking process, from the 'ex ante stage' all the way through to the actual utilization stage.⁵ And learning costs seem to occur mainly in the first stages of the help-seeking process, with compliance costs occurring later on in the process – even though the latter could not be further illustrated in more detail due to low actual service use amongst the respondents.

Secondly, the empirical findings indicate that different administrative burdens are interrelated. Some types of learning costs and (expected) compliance costs have, at the same time, 'psychological repercussions' for caregivers. Related to this, there are clear indications that this co-occurrence produces a cumulative negative effect on the help-seeking process. The latter also applies to different psychological costs occurring simultaneously and reinforcing one another. For example, when there is a strong cultural-psychological norm of taking care of one's own family, as well as the perception that asking for help from a third sector provider is going to bring about a lot of hassle. Still, although the

⁵ Where research on administrative burdens in another context, namely that of voluntary programs, hypothesizes that "psychological costs matter less" (Carter, Scott & Mahallati, 2018: p. 214), in the context that is under scrutiny here, help-seeking for social support, psychological costs actually appear to matter quite a lot.

current study provides some indications of a link between different types of costs, more empirical research is required to further flesh out their interrelationship. Nevertheless, the added value of the concept of administrative burden is that it provides a way to disentangle different factors in the help-seeking process and to meaningfully relate them.

The third and final implication is about the relation between the subjective experience and/or perception of administrative burdens and the more rational-cognitive aspects in help-seeking behavior. This study indicates that the subjective experience of burdens, or the subjective perception thereof, can 'override' the more rational-cognitive elements in help-seeking. This is mainly observed in how otherwise competent caregivers perceive high costs when it comes to finding, accessing and utilizing social support services that are designed to help them. Differently put: in one domain, they are highly organized and effective, while in the other domain, these rational-cognitive skills are not (always) put to use when it comes to organizing their own support. Hence, conceptually, it is important to also incorporate the more rational-cognitive elements of help-seeking, in particular the role of (bureaucratic) competences – without having to abandon current assumptions of help-seeking behavior.

Summary

The administrative burdens that (potential) welfare recipients perceive or experience are the result of a still poorly understood interplay of different (f)actors at different levels of the social service system. This chapter has contributed considerably to solve that larger puzzle. Now, we have a better understanding of the administrative burdens that a group of hard-to-reach caregivers perceive and experience in their daily lives. We now know more about how such burdens lead to the non-take-up of social support services that are specially designed for, and offered to caregivers by third sector organizations. The next paragraph briefly recapitulates the yields of this study and concludes this chapter.

5. CONCLUSION

The concept of administrative burdens has shown to be very useful to better understand how bureaucratic barriers affect the help-seeking process of hard-to-reach caregivers. This theoretical concept allows one to move beyond the rather superficial – even gratuitous –

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'bureaucracy bashing' that sometimes manifests itself within the academic literature. It allows for a more nuanced understanding of bureaucratic barriers. It allows to identify, describe and interpret different types of costs in the various stages of the help-seeking process. Importantly, this study has adopted a broader conception of help-seeking, by looking at the whole *process* instead of merely concentrating on *realized access*, or the rather narrow question if support was utilized yes or no – as many other studies do. The empirical findings indicate and illustrate that different types of learning costs and psychological costs are highly pronounced in different stages of the help-seeking process. Most prevalent were psychological costs and learning costs that occur in the early stages of help-seeking. In addition, different types of *ex ante* psychological costs were identified, as well as psychological costs that co-occur with learning costs and (expected) compliance costs – together producing cumulative negative effects on help-seeking for social support.

In terms of learning costs, all types that are distinguished by Moynihan, Herd & Harvey (2015) were observed. Potential participants have to learn about the program, know the eligibility criteria, understand the nature of the services that are offered, and, finally, how they may access services. Within all samples of caregivers there were low levels of knowledge/awareness about the supply of support services for caregivers. When one realizes that there are more than four thousand third sector organizations in The Hague that offer some form of social support for caregivers, this lack of awareness is quite striking. And that the vast majority of our samples consisted of seasoned caregivers, makes that even more remarkable. Furthermore, whereas professionals, such as GPs, are supposed to inform them about available support services, this appeared not to be the case amongst caregivers in this study. Moreover, some variance was observed between different socio-cultural groups of caregivers. Especially non-Dutch speaking caregivers face even higher learning costs due to language barriers. Due to the low levels of service use amongst respondents, there was not much data on (perceived) compliance costs. Follow-up research is necessary amongst more caregivers that have used social services from third sector providers, in order to draw more meaningful conclusions in relation to that component of administrative burdens.

Important to note is that the current findings do not allow for generalization to the total population – or subpopulations, for that matter – of caregivers, as this study includes the perceptions and experiences of a relatively small group of caregivers in one Dutch municipality. Still, the qualitative research design and the use of focus groups did allow for an in-depth understanding of the influence of administrative burdens on help-seeking behavior of caregivers that are difficult to reach – both for practitioners as well as researchers. Reaching those difficult-to-reach caregivers and documenting their lived experiences, to get a grasp of the problems and barriers they encounter, to understand their reasons for not asking for social support, is vital to (further) improve social policies and social service delivery. Hopefully this study sparks a fruitful dialogue and exchange amongst all those that take an interest in the non-take-up of social support, and who aspire to fully grasp all the intricacies and complexities of the ubiquitous, yet opaque phenomenon of non-take-up of social support.

LITERATURE

Andersen, R.M. (2008). National health surveys and the behavioral model of health services use. *Medical care*, 647-653.

Bozeman, B. (2000). *Bureaucracy and red tape*. Prentice Hall.

Burden, B.C., Canon, D.T., Mayer, K.R., & Moynihan, D.P. (2012). The effect of administrative burden on bureaucratic perception of policies: Evidence from election administration. *Public Administration Review*, 72(5), 741-751.

Carter, D.P., Scott, T.A., & Mahallati, N. (2018). Balancing barriers to entry and administrative burden in voluntary regulation. *Perspectives on Public Management and Governance*, 1(3), 207-221.

Groeneveld, S., Tummers, L., Bronkhorst, B., Ashikali, T., & Van Thiel, S. (2015). Quantitative methods in public administration: Their use and development through time. *International Public Management Journal*, 18(1), 61-86.

Moynihan, D., Herd, P., & Harvey, H. (2015). Administrative burden: Learning, psychological, and compliance costs in citizen-state interactions. *Journal of Public Administration Research and Theory*, 25(1), 43-69.

Moynihan, D.P., Herd, P., & Ribgy, E. (2016). Policymaking by Other Means: Do States Use Administrative Barriers to Limit Access to Medicaid? *Administration & Society*, 48(4), 497-524.

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PEP Den Haag (2016). *Rapport respijtzorgonderzoek. Inventarisatie respijtzorg 2016 in Den Haag & Criteria en draagvlak voor de vernieuwing van de Respijtwijzer*, retrieved from https://denhaagmantelzorg.nl/var/downloads/var/mediamanager/files/Rapport_respijtzorg_onderzoek_Den_Haag.pdf

Pommer, E., Boelhouwer, J., Eggink, E., Marangos, A.M. & Ooms, I. (2018) *Overall rapportage sociaal domein 2017. Wisselend bewolkt*, The Hague: The Netherlands Institute for Social Research (SCP).

Reijnders M.A.W. & Truijens D. (2015), Business as (un)usual? The future of informal care networks in The Netherlands, *The Hague Governance Quarterly* 4(1).

Reijnders, M. A. W., Schalk, J., & Steen, T. P. S. (2017). Wie niet vraagt, die niet wint: Een literatuurverkenning naar de determinanten van vraagverlegenheid voor vrijwillige inzet. *Bestuurskunde*, 26, 12.

Reijnders, M., Schalk, J., & Steen, T. (2018). Services Wanted? Understanding the Non-take-up of Social Support at the Local Level. *VOLUNTAS: International Journal of Voluntary and Nonprofit Organizations*, 29(6), 1360-1374.

Sannen, L. (2003). Drempels naar welzijnsvoorzieningen: de cliënt aan het woord. Literatuurstudie en diepte-interviews bij kansarmen en etnisch-culturele minderheden. Leuven: Katholieke Universiteit Leuven, HIVA.

Shaghghi, A., Bhopal, R.S., & Sheikh, A. (2011). Approaches to recruiting 'hard-to-reach' populations into research: a review of the literature. *Health Promotion*, 1(2), 01-09.

Taleb, N.N. (2007). *The black swan: The impact of the highly improbable (Vol. 2)*. Random House.

Van Exel, J., Morée, M., Koopmanschap, M., Goedheijt, T.S., & Brouwer, W. (2006). Respite care – an explorative study of demand and use in Dutch informal caregivers. *Health Policy*, 78(2-3), 194-208.

Van Oorschot, W.J.H. (1995). *Realizing rights: a multi-level approach to non-take-up of social security benefits*. Avebury: Aldershot.

Van Oorschot, W.J.H. (1998). Failing selectivity: On the extent and causes of non-take-up of social security benefits. In H.-J. Andress (Ed.), *Empirical poverty research in a comparative perspective* (pp. 101–132). Aldershot: Ashgate.

Zarit, S.H., Pearlin, L.I., & Schaie, K.W. (1993). *Caregiving systems: Informal and formal helpers*. Psychology Press.

[list to be completed]