Caregiving experiences of informal caregivers
Oldenkamp, Marloes

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General introduction
This is a study about the conditions related to negative and positive caregiving experiences of informal caregivers. This is accomplished by evaluating how variations in negative and positive caregiving experiences can be explained by the characteristics of the informal caregiver, the health situation of the care recipient, the care situation in which informal care is provided, and the possible spill-over of informal caregiving to other life domains such as paid work. This information is crucial for prioritizing areas for policy action and the development of effective caregiver support.

Population Ageing and Increasing Pressures on National Healthcare Systems

The proportion and absolute number of older persons is increasing worldwide (1). This population ageing has two main drivers: increasing life expectancy and falling fertility rates (1). While in 1950 less than 1% of the global population was aged 80 years or older, it is expected that the share of people aged 80 years and over increases from 4% in 2010 to nearly 10% in 2050 in OECD countries (2). As people age, they are more likely to suffer from (chronic) diseases and disorders, and more likely to experience multimorbidity (i.e., the presence of multiple chronic conditions at the same time), which is associated with higher rates of healthcare utilization and with higher healthcare costs (3). Because care dependency increases with age, the ageing of the population will lead to increased healthcare needs. Fulfilling these increasing healthcare needs puts a pressure on the financial sustainability of national healthcare systems and informal caregivers (4).

Changes in the Dutch Long-Term Care System

In the Netherlands, the increasing pressure on the national healthcare system has led to significant changes in the long-term care system. With the reforms, the government aims at making the long-term care more financially sustainable, improving the quality of the care, helping people to become more independent and continue living at home longer, and strengthening the position of informal caregivers. In the new system, long-term care is now arranged in three different regulations/acts: the Long-Term Care Act (Wet langdurige zorg (Wlz)), the Care Insurance Act (Zorgverzekeringswet (Zvw)), and the renewed Social Support Act 2015 (Wet maatschappelijke ondersteuning (Wmo 2015)) (5).

The Wlz replaces the old Exceptional Medical Expenses Act (Algemene Wet Bijzondere Ziektekosten (AWBZ)). Care provided through the Wlz remained the responsibility of the central government, but the amount of care that is covered is substantially less compared to the old AWBZ. The Wlz focuses on institutional care, which is only available to people with severe care needs, for example, 24 hours supervision or permanent care. For many types of less intensive care, the responsibility has shifted to local authorities and care insurers. Care insurers are now responsible for delivering community nursing services (personal care and nursing), which is arranged in the Zvw.
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**POPULATION AGEING AND INCREASING PRESSURES ON NATIONAL HEALTHCARE SYSTEMS**

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**CHANGES IN THE DUTCH LONG-TERM CARE SYSTEM**

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needs assessment is carried out by community nurses, in which they are expected to incorporate the presence and contribution of informal caregivers in fulfilling care needs.

With the renewed Social Support Act 2015 (Wmo 2015), the responsibility of local authorities for the provision of social support increased, and this decentralization went along with financial budget restrictions. Municipalities are responsible for social support for people who are unable to cope on their own or unable to fully participate in society. Local authorities are stimulated to provide support more efficiently, for example by using more informal care. The new Wmo 2015 is based on people’s own strengths and self-reliance, and emphasizes people’s own responsibility to meet their healthcare needs (the so-called ‘participatiemaatschappij’). In their assessment and decision on the provision of help and support, municipalities now take into account the person’s social network, including the availability of informal caregivers. Wmo-funded support, such as domestic help, shopping services or transport services, is provided in addition and complementary to the help and support of the social network.

THE NETHERLANDS VERSUS OTHER (EUROPEAN) COUNTRIES

Concerns about the financial sustainability of the long-term care system have become a prominent policy issue not only in the Netherlands, but in many (European) countries (6), and informal care has been brought into the limelight in many countries (7). Although all countries face population ageing, countries are less comparable in how they structure, and possibly reform, their long-term care system (8). For example, countries vary in their generosity of resources available for formal long-term care and in their national policies that provide services for informal caregivers (e.g, training and counselling, respite care (informal care temporarily being taking over, during daytime or overnight), paid and unpaid leave from work or flexible work arrangements) (9). However, two policy trends can be identified among European countries, and these trends can also be observed in the Netherlands (8). One, in countries with a large amount of publicly funded care, the focus is increasingly shifting towards family or social responsibility, including the promotion of informal care. In countries in which informal care is already dominating, informal care remains important, but efforts are made to improve the accessibility and quality of the publicly funded care (8). Two, regional and local authorities are becoming more important for the organisation and regulation of care. This is based on the assumption that care provision organized close to the care recipient leads to more appropriate care solutions (8).

Within Europe, three clusters of countries are often distinguished: A Northern cluster (comprising the Netherlands, Sweden and Denmark), a Central European cluster (Austria, France, Belgium and Germany) and a Southern and Eastern European cluster (Italy, Spain, Portugal, Estonia, Hungary, Czech Republic, Poland, Slovenia and Switzerland) (8). In general, a high public spending and low family responsibility characterizes countries in the Northern cluster, while countries in the Southern and Eastern European cluster are characterized by low public spending and high family responsibility. The Central European cluster is characterized by average public spending and average family responsibility (8). Despite the clustering of countries, the role of the government in the organization
and funding of long-term care versus the level of individual and family responsibilities is one of the most important differences among countries (10). This makes it difficult to compare countries, also within these clusters. This thesis mainly concerns the Dutch situation, and study results cannot simply be translated to other countries. When generalizing study results to other countries, this needs to be done in light of differences between countries, national policies, and (reforms of) long-term care systems.

DEFINITION OF INFORMAL CARE

There is no standardized definition of informal care, but three main criteria characterize informal care. First, informal care arises from a mutual relationship between the informal caregiver and the person receiving the care (i.e., the care recipient). There is a social relationship, for example between spouses, parent and child, other relatives, friends, or neighbours, that already existed prior to the situation in which informal care is provided by one to the other (11). This pre-existing social relationship is also an important difference between informal care and voluntary work in the care sector (12, 13). Second, informal care includes care that is provided because of health problems of the care recipient, like impairments or disabilities/disorders, chronic mental health or psychosocial problems, or problems due to old age, and that is not provided by health care professionals (11). And third, informal care exceeds usual care (‘gebruikelijke hulp’). Usual care is the normal, everyday care that household members (i.e., spouses, parents, resident children, other household members) are generally expected to provide to each other, such as household tasks like cleaning or cooking (11, 14). Care that exceeds this usual care is no longer considered as usual care, but as informal care. Informal care includes a wide range of activities, like help with financial and administrative matters, gardening, help with household tasks (e.g., grocery shopping, cooking, cleaning), personal care (e.g., washing, toileting, getting dressed and undressed), emotional support and supervision, help with medication use/administration, and help with transport to social activities and contacts, GP visits, or other health care visits.

INFORMAL CAREGIVERS IN THE NETHERLANDS

In the Netherlands in 2014, about 4.3 million people aged 18 years and over had provided some type of informal care in the past year. This was 33% of the Dutch adult population (11). Among these 4.3 million informal caregivers, around 610.000 (5% of adult population) had provided this informal care for more than 8 hours a week and for a period longer than 3 months (11). In the total Dutch adult population, women provided more often informal care than men (37% versus 28%) and people aged 45-64 years provided more often informal care than people in other age categories (39% versus 20-33% in other age categories). Within the population of informal caregivers, four out of five cared for a relative, most often their parent (in-law) (45%) or their partner (14%). About one in five informal caregivers cared for a friend (16%) or neighbour (6%) (11).
STRENGTHENING THE POSITION OF INFORMAL CAREGIVERS

As a result of the population ageing and the changes and developments in the Dutch long-term care system, more demands are being placed on people and their social networks, including their informal caregivers. This makes informal care of great value for the Dutch healthcare system. The use of informal care is also expected to increase in the future. A study of the Netherlands Institute for Social Research suggested an increase of 8% between 2009 and 2030 of the number of people aged 30 and over making use of informal care (15). With the introduction of the new Wmo 2015, the government intends to improve and strengthen the position of informal caregivers (16). Municipalities have the responsibility to support informal caregivers so that they can fulfil their role as informal caregiver. Examples of support for the informal caregiver in the Wmo 2015 are respite care (informal care temporarily being taken over, during daytime or overnight), information, advice, financial support, or domestic help for the care recipient to relieve the informal caregiver (11).

Whether informal caregivers indeed are able to provide informal care without problems and feelings of strain or burden may be questioned, as informal care organisations, representatives and interest groups (e.g., Mezzo, Werk&Mantelzorg, Vilans) increasingly report about the difficulties and problems informal caregivers are facing. For example, informal caregivers may have problems with combining their care tasks with other activities such as paid work, child care, and social life, they may experience informal caregiving as a (severe) strain, or they may even become ill or feel highly burdened as a result of their caregiving (11). In 2014, about one out of ten informal caregivers in the Netherlands (approximately 400.000 people) felt highly burdened as a result of the informal care they provided. They felt they were too tired to undertake other activities, experienced conflicts at work or at home due to the provision of informal care, or even became ill as a result of their informal care (11).

INFORMAL CAREGIVERS HAVE NEGATIVE, BUT ALSO POSITIVE CAREGIVING EXPERIENCES

On the one hand, the problems reported by informal care organizations, representatives and interest groups of informal caregivers are in line with what is often reported in caregiving research. Caregiving literature shows that informal caregivers experience more health problems, are more stressed and depressed, have lower levels of subjective well-being, and lower levels of physical health, compared to people who do not provide informal care (17, 18). In a sample of older spousal caregivers and non-caregiving controls, it was even found that being an informal caregiver experiencing caregiver strain (mental or emotional strain) may be an independent risk factor for mortality after four years of follow-up (19).

However, on the other hand, informal caregiving can be enriching and satisfying, making it a positive experience as well (20-22). For instance, informal care provision can provide feelings of reward, love and appreciation, enjoyment, personal growth, and gain (21, 23-25). The majority of informal
caregivers experiences some or more positive aspects of caregiving. Cohen et al. (26) showed that almost three quarters (73%) of informal caregivers of seniors living in the community identified at least one positive aspect of caregiving, and an additional 7% identified two or more positive aspects of caregiving. These positive caregiving experiences can improve the adaptation of informal caregivers to difficult caregiving situations. For example, when informal caregivers experience more uplifts of caregiving, find meaning in their caregiving experience, or have more positive feelings about caregiving, they experience lower caregiver burden and depression (27), are better able to adapt to the caregiving situation (28), and have better self-assessed health (26). Existing research also suggests that caregiving stressors are related to both negative and positive caregiving experiences, but in different ways (29-33). This indicates that informal caregivers may have both negative and positive caregiving experiences at the same time.

**MAIN OBJECTIVE OF THE THESIS**

With the demographic trend of population ageing and the reforms of the long-term care system, the needs for care and the pressure on people to provide informal care are increasing. At the same time, informal care provision can have negative consequences for informal caregivers. These developments could form a potential time bomb, unless clear insights are gained on the possibilities to reduce negative caregiving experiences and, in addition, to enhance positive caregiving experiences. Therefore, the main objective of this thesis is to study how variations in negative and positive caregiving experiences can be explained by characteristics of the informal caregiver, the health situation of the care recipient, the care situation in which informal care is provided, and the possible spill-over of informal caregiving to other life domains such as paid work.

A full understanding of the caregiving experience is essential for the development of effective caregiver support. This requires the incorporation of both the negative experiences of caregiving, such as negative health effects and possible spill-over to other life domains such as paid work and social life, and the positive experiences that informal caregivers may have when providing informal care. In addition, the nonresponse of informal caregivers in caregiving research is evaluated. Insights in the factors that relate to the research participation and nonresponse of informal caregivers are crucial for the study of negative and positive caregiving experiences. Without this information, we do not know to what extent study findings are generalizable to a larger group of informal caregivers. However, only little is known about the nonresponse of informal caregivers in caregiving research. It has been suggested that being an informal caregiver is related to a higher nonresponse (34), but questions about whether and which characteristics of the informal caregiver, care recipient, and the caregiving situation relate to nonresponse of informal caregivers, remained largely unanswered.
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THE CAREGIVING STRESS PROCESS MODEL

A widely used framework to study the complex interplay between characteristics of the informal caregiver, care recipient and care situation, and the development of negative caregiving outcomes such as burden or stress, is the caregiving stress process model (35). In this model caregiving is assumed to be a stressful experience, and a distinction is made between primary stressors and secondary stressors. Primary stressors directly stem from the health problems and care needs of the care recipient and the related types and amount of informal care provision, and have a negative impact on the caregiving experience. For example, informal caregivers who provide more hours of care a week, or who provide long-term informal care (i.e. longer caregiving duration), have more negative caregiving experiences such as burden or depression (27). In addition, the care recipient’s level of physical impairments and behavioural problems positively relate to the level of negative caregiving experiences (27).

Secondary stressors also contribute to caregiver burden and stress. They concern the difficulties in other life domains that follow from the provision of informal care, such as interferences with work, financial strain, family conflict, or decreased leisure time. Research has shown that, for example, the experience of difficulties with the combination of paid work and informal care is associated with high caregiver burden (36-39) poor well-being (38, 40-42), and a higher work-related strain (43) among informal caregivers.

Informal caregivers who face similar primary and/or secondary stressors may experience different levels of burden or stress. This depends on the factors that may ameliorate or exacerbate the primary and/or secondary stressors, like social support, or coping strategies (35), but also attitudinal or relational factors (27, 44). These are factors that can alleviate caregiving stressors, but can also exacerbate caregiving stressors in case they are lacking, like knowledge or information, coping resources, or quality of the relationship between informal caregiver and care recipient (45).

For negative caregiving outcomes, the applicability of the caregiving stress process model has been demonstrated in multiple studies (27, 46, 47). However, the extent to which primary stressors, secondary stressors, and alleviating/exacerbating factors also relate to positive caregiving experiences has been studied less extensively (29, 48). Primary and secondary stressors may relate to negative and positive caregiving experiences in different ways (29-32), which urges a thorough study of the role of primary and secondary stressors for positive caregiving experiences. In this thesis both primary stressors, secondary stressors, and exacerbating or ameliorating factors are studied in relation to positive and negative caregiving experiences.

RESEARCH DESIGN AND DATA

Lifelines Cohort Study and Lifelines Informal Care Add-on Study

Four studies in this thesis (Chapters 2, 3, 6, and 7) are based on data from the Lifelines Cohort Study and the Lifelines Informal Care Add-on Study (Lifelines ICAS). The Lifelines Cohort Study is a large...
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multi-disciplinary prospective population-based cohort study examining in a unique three-generation design the health and health-related behaviours of 167,729 persons living in the North of the Netherlands (49, 50). Baseline assessment took place between 2006 and 2013 and was performed at 12 local Lifelines research sites. Participants are followed up with questionnaires (self-report) every 1.5 years and comprehensive physical examinations every 5 years.

The Lifelines informal care add-on study (Lifelines ICAS) was conducted within the Lifelines Cohort Study. Between May 2013 and July 2014, a questionnaire was distributed among all Lifelines participations who were identified as informal caregiver and who gave consent to participate in Lifelines ICAS, resulting in a sample of 965 informal caregivers. The informal care questionnaire covered a wide range of themes related to informal caregiving, such as the health situation of the care recipient, the types and number of informal care tasks, negative and positive caregiving experiences, and the combination of informal care and paid work.

National Care for the Elderly Programme and The Older Persons and Informal Caregivers Survey Minimum DataSet

Two studies in this thesis (Chapters 4 and 5) are based on data collected within the National Care for the Elderly Programme, which is conducted by the Netherlands Organization for Health Research and Development, on behalf of the Ministry of Health, Welfare and Sport. The National Care for the Elderly Programme is designed to improve the quality of care for older persons with complex care needs by developing coherent care that is better suited to the individual needs of older person. It started in 2008 and ran until 2016. In December 2016, more than 125 research projects had been funded.

One study (Chapter 4) is based on data from a cohort study investigating the health care needs of older adults, which was set up within the infrastructure of the Network Elderly Care Region North. This network is part of The National Care for the Elderly Programme. Another study (Chapter 5) is based on data from The Older Persons and Informal Caregivers Survey Minimum DataSet (TOPICS-MDS) (51, 52). TOPICS-MDS is a public data repository, developed to combine the information collected in all the research projects that are funded by the National Care for the Elderly Programme. All research projects included uniform and validated instruments to measure the physical, psychological, and social health and well-being of older persons and their informal caregivers. The TOPICS-MDS database (TOPICS-MDS version 2, 2014) contains baseline data of 37,692 older persons and 3940 informal caregivers, derived from 42 research projects (52).

OUTLINE OF THE THESIS

In Chapter 2 the study design, data collection procedures, measurements, and study population of the Lifelines Informal Care Add-on Study (Lifelines ICAS) is described. In Chapter 3 the nonconsent and nonresponse bias in the sample of 8443 informal caregivers who participated in the Lifelines Cohort Study and were invited for participation in Lifelines ICAS is examined. Consent and nonconsent
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caregivers, and response and nonresponse caregivers are compared on socio-demographic characteristics, caregiver health, caregiving situation, and caregiver outcomes. In addition, the influence of nonconsent and nonresponse on the associations between caregiver characteristics and caregiver burden and satisfaction is evaluated. In Chapter 4 the associations of primary caregiving stressors (time investment in caregiving, care recipient’s health situation) with overall caregiver burden and multiple burden dimensions among 154 spousal and 202 adult-child caregivers are studied, both cross-sectional and longitudinal (12-months follow-up). This study is conducted with data from a cohort study that was set up within The National Care for the Elderly Programme. Chapter 5 evaluates in greater detail the associations of (changes in) the care recipient’s health situation with care-related quality of life, containing two positive and five negative dimensions, experienced by 660 informal caregivers. Frailty and multiple health domains of frailty are used as indicators of the care recipient’s health situation. This study is based on baseline and 12 months follow-up data from The Older Persons and Informal Caregivers Survey Minimum DataSet (TOPICS-MDS). Chapter 6 is conducted with data of 660 informal caregivers, collected in Lifelines ICAS, and presents the results of a study investigating the importance of attitudinal and relational factors (exacerbating/ameliorating factors) for both negative and positive caregiving experiences. In addition, the importance of the complexity and amount of informal care provided (primary stressors) and of the impact of caregiving on other life domains (secondary stressors) for both negative and positive caregiving experiences is studied. In Chapter 7 the use of work arrangements by 333 working adult-child caregivers participating in Lifelines ICAS is studied. This chapter explores what types of work arrangements (taking time off, formal care leave arrangements, individual agreements with supervisor, reduction of paid work hours) are used by working adult-child caregivers, and whether care, work, and caregiver characteristics are associated with the use of these work arrangements. Chapter 8 discusses the main research findings of this thesis, the implications of the research findings, methodological considerations, and directions for future research.
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