Summary
Summary

This thesis concerns the conditions related to negative and positive caregiving experiences of informal caregivers. Information about these conditions is crucial for prioritizing areas for policy action and the development of effective caregiver support.

The proportion and absolute number of older persons is increasing worldwide, resulting in increasing healthcare needs. Fulfilling these increasing healthcare needs puts a pressure on national health care systems and on informal caregivers. 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, which was 33% of the Dutch adult population. About one in ten of them (approximately 400,000 people) felt highly burdened as a result of the informal care they provided. However, the majority of informal caregivers also experiences positive aspects of informal caregiving, such as feelings of reward, enrichment, personal growth or love and appreciation. Existing research suggests that informal caregivers can have both negative and positive caregiving experiences at the same time, and that negative and positive caregiving experiences might be related to different aspects of the informal care situation. With the demographic trend of population ageing and the reforms of the long-term care system, the needs for care increase and the pressure on people to provide informal care increases as well. At the same time, informal care provision can have negative consequences for informal caregivers. These developments require clear insights on the possibilities to reduce negative caregiving experiences and, in addition, to enhance positive caregiving experiences. In this thesis, it was studied if and 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.

Chapter 2 describes the study design, data collection procedures, measurements, and study population of the Lifelines Informal Care Add-on Study (Lifelines ICAS). Lifelines ICAS was initiated within the Lifelines Cohort Study to cover the large heterogeneity in the caregiver population, and to investigate the interplay among characteristics of the informal caregiver, care recipient, and care situation and positive and negative caregiver experiences and outcomes. Lifelines participants who were self-identified as informal caregiver (N=11,651) provided basic information about their care situation. A subsample of informal caregivers (N=2002) was invited for participation in Lifelines ICAS, and eventually 965 informal caregivers participated in Lifelines ICAS (response rate 48%). They completed a comprehensive questionnaire about their care situation and caregiving experiences. The Lifelines ICAS study population contained a wide mixture of informal caregivers, with variation in, for example, types of informal care tasks, intensity of caregiving, care recipient’s health problems, and caregiving experiences and outcomes. This wide variation enables the study of not only differences but also common correlates of negative and positive caregiving experiences such as caregiver burden and caregiver satisfaction.

In Chapter 3 we evaluated the nonconsent and nonresponse bias in the sample of informal caregivers who participated in the Lifelines Cohort Study and were invited for participation in Lifelines ICAS. We
found that informal caregivers who were highly involved in caregiving (i.e. high time investment, high caregiver burden) were more likely to give consent for participation in Lifelines ICAS, and that they were also more likely to respond to and return the informal care questionnaire of Lifelines ICAS. The nonconsent and nonresponse affected the associations between some caregiver characteristics and caregiver burden. These caregiver characteristics were mainly indicators of the level of caregiving involvement, such as the time investment in caregiving and the caregiving duration. The associations between these indicators and caregiver burden were stronger for consent and response caregivers than for nonconsent and nonresponse caregivers. This emphasizes that not all informal caregivers will participate in caregiving studies and that participation might not be evenly distributed among informal caregivers. Moreover, some associations with caregiver burden might be overestimated, and the possibility of nonconsent and nonresponse bias needs to be considered in caregiving research.

In Chapter 4 the associations were examined between several primary caregiving stressors (e.g., hours of informal caregiving a week, care recipient’s health problems) and overall caregiver burden and multiple dimensions of caregiver burden, as experienced by 154 spousal caregivers and 202 adult-child caregivers of Dutch older adults, both cross-sectional and longitudinal (12-months follow-up). For this study data was used from a cohort study that was set up within The National Care for the Elderly Programme. Considerable differences were found between spousal and adult-child caregivers with regard to their care situation and levels of subjective burden. For example, spousal caregivers provided on average more hours of household care tasks compared to adult-child caregivers, and adult-child caregivers cared for a care recipient with on average more health problems compared to spousal caregivers. At both baseline and follow-up, spousal caregivers experienced a higher overall caregiver burden and experienced more often mental health problems, physical health problems, and problems with combining their daily activities, compared to adult-child caregivers. In addition, a poorer care recipient’s health situation was associated with higher subjective burden among spousal caregivers, while adult-child caregivers reported higher levels of subjective burden when their time investment in caregiving was high. At follow-up, the level of subjective burden was mainly explained by baseline subjective burden, for both spousal and adult-child caregivers. These findings demonstrate that spousal and adult-child caregivers provide informal care in different caregiving situations, that they may experience different levels and types of caregiver burden, and that these burdens may be associated to different (primary) caregiving stressors. This underscores that the type of care relationship should be taken into account in the (development of) support for informal caregivers. Furthermore, the current health situation of the care recipient and the current time investment in caregiving are important predictors of subjective burden over time, and should therefore be taken into account in the prevention of future caregiving burden.

Chapter 5 evaluated whether changes in an older person’s frailty over time influence the care-related quality of life experienced by their informal caregiver. In addition to overall frailty and care-related quality of life, we studied multiple health domains of frailty and multiple negative and positive
Summary

dimensions of care-related quality of life. A sample of 660 older person/caregiver couples was derived from 5 research projects in the TOPICS-MDS database (The Older Persons and Informal Caregivers Survey Minimum Data Set) with data of both the older person and informal caregiver at baseline and 12-months follow-up. An increase in frailty of the care recipient over time, and especially a change in the care recipient’s psychological well-being, turned out to be related to a lower care-related quality of life of the informal caregiver at follow-up. This lower care-related quality of life was particularly reflected in more mental and physical health problems and more problems with combining informal care tasks with other daily activities. An increase in the hours of informal caregiving over time also negatively affected the caregivers care-related quality of life. Positive dimensions of care-related quality of life, like fulfilment from caregiving, were not affected by changes in frailty or hours of informal caregiving. These results show that a deteriorating health situation of older persons (i.e. an increase in frailty) can have a negative impact on the care-related quality of life of their informal caregivers. Health professionals who observe an increasing frailty or decreasing psychological well-being of an older person, or who observe an increase in the hours of informal care provision, should be aware of the considerable problems this may bring to the informal caregiver. Caregiver interventions to support the informal caregiver should be discussed, and this support needs to be tailored according to the specific needs and problems of the informal caregiver.

In Chapter 6 we studied the role of the quality of the relationship between informal caregiver and care recipient and intrinsic caregiving motivations on both negative and positive caregiving experiences, independently from primary and secondary caregiving stressors. In addition, we explored the potential buffer- and thrive-effects of relationship quality and intrinsic caregiving motivations. Based on a sample of 660 informal caregivers from Lifelines ICAS, we found that informal caregivers with high intrinsic caregiving motivations who provided care in a high quality relationship had more positive caregiving experiences, but did not experience less negative caregiving experiences. In addition, intrinsic caregiving motivations buffered decreases in positive caregiving experiences. A thrive-effect could not be demonstrated (i.e., caregivers did not have more positive caregiving experiences when they faced high stressors in a high quality relationship or with high intrinsic caregiving motivations). For negative caregiving experiences primary and especially secondary stressors were important; the impact of caregiving in other life domains such as work, social activities, and health turned out to be important for negative outcomes such as caregiver burden. These results suggest that special attention for caregivers with low relationship quality and low intrinsic caregiving motivations is needed in policy making and interventions. A negative spill-over of caregiving into other life domains needs to be prevented as well. Policy makers and important stakeholders should be aware of this, and should pay more attention to risk groups with high stressors like the provision of many hours of types of informal care and the negative spill-over to other life domains. It is important to develop suitable interventions in order to reduce this negative spill-over.
Chapter 7 explored what types of work arrangements are used by working adult-child caregivers, and whether care, work, and caregiver characteristics are associated with the use of work arrangements. In a sample of 333 working adult-child informal caregivers, derived from Lifelines ICAS, the majority (61%) had used one or more work arrangements, which was most often taking time off (41%), followed by individual agreements with the supervisor (30%), a formal care leave arrangement (13%), and a reduction of paid work hours (6%). Working adult-child caregivers with long working hours, who experienced more health problems or more often experienced a disrupted schedule due to their informal caregiving, were more likely to have used one or more work arrangements. This suggests that in such a severe care situation, working caregivers have to adapt their paid work situation more often in order to combine their paid work and informal care tasks. Since almost half of the working adult-child caregivers did not use any work arrangement, policy makers and employers should inform working informal caregivers about the existence and availability of the various options of work arrangements. In addition, employers need to consider whether they need to adopt a more caregiver-friendly policy. Specific attention could be paid to lower educated working adult-child caregivers when addressing formal care leave arrangements, because in this study they were less likely to have used a formal care leave arrangement.

Chapter 8 comprises the general discussion in which the main research findings and their implications are discussed, followed by several methodological considerations and directions for future research. First of all, we found that negative caregiving experiences are mainly related to primary (hours and types of informal care provision) and secondary stressors (health problems and problems with combining daily activities due to informal care provision), while positive caregiving experiences are mainly related to intrinsic caregiving motivations and the quality of the relationship between informal caregiver and care recipient. This means that caregiver support interventions in which negative caregiving experiences are successfully addressed, may not always be successful in improving positive caregiving experience. Such interventions may need another focus, for example on an improved relationship quality between informal caregiver and care recipient or on an increase in the informal caregiver’s level of intrinsic caregiving motivations. The identification, incorporation and evaluation of (other) factors that enhance positive caregiving experiences in caregiver interventions is an important topic for future caregiving research. Second, spousal and adult-child informal caregivers provide informal care in different care situations, and the presence and strength of the associations of some stressors with negative caregiving experiences varies for spousal and adult-child caregivers. This indicates that not all types of support may be beneficial for all types of informal caregivers, and emphasizes the importance of incorporating the type of care relationship in the development and provision of effective caregiver support. Third, the spill-over from informal caregiving to other life domains such as paid work, is associated to negative caregiving experiences and can result in adaptations at the workplace. Receiving information about the options of, for example, the use of formal care leave arrangements, or being stimulated to discuss their situation with employers, supervisors and colleagues can be important for working informal caregivers. This may reduce and prevent the burden and stress arising from problems with combining paid work...
Summary

with informal care, which contributes to a sustainable employability of working informal caregivers. The study of work characteristics that may influence whether working caregivers feel entitled to take formal care leave (their ‘sense of entitlement’), such as job type or attitudes and opinions of employers and colleagues, can contribute to this sustainable employability as well.

The study of informal caregiving turned out to be complex, as many different factors play a role and can be related to each other as well. This also depends on aspects like the type of care relationship, the health situation of the care recipient, and the intensity of informal caregiving. Due to this complexity, large sample sizes are important in order to answer the research questions of main interest, and each time it should be considered whether or not to focus on a selection of informal caregivers. The inclusion of all relevant factors in caregiving studies is hampered by the aim to limit the burden of research participation for informal caregivers. Moreover, research participation might not be evenly distributed, and the possibility of nonconsent and nonresponse bias needs to be taken into account.