Caregiving experiences of informal caregivers
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General discussion
INTRODUCTION

The main objective of this thesis was to enhance the understanding of the informal caregiving experience, by studying how variations in negative and positive caregiving experiences can be explained by a broad range of factors, including 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. In light of developments such as population ageing and reforms of long-term care systems, information about the conditions that relate to negative and positive caregiving experiences of informal caregivers is crucial for prioritizing areas for policy action and the development of effective caregiver support. All studies in this thesis were based on data collected in the Netherlands. Although many other (European) countries face population ageing, and informal care has increased in importance in many countries (1, 2), countries differ in the organization of their long-term care, the level of individual and family responsibilities, and their support for informal caregivers (3, 4). Therefore, when generalizing study results to other countries, differences between countries, national policies, and reforms of long-term care systems need to be taken into account.

Evaluating the factors that are associated with the level of negative and/or positive caregiving experiences is complex, as many of these factors are associated with negative and positive caregiving experiences in different ways, depending on the caregiving situation and the characteristics of the informal caregiver and care recipient. This final chapter provides a summary of the main research findings, a discussion of the implications of these research findings, a discussion of methodological considerations, and directions of future research.

MAIN RESEARCH FINDINGS

Negative and positive caregiving experiences are related to different factors

The first main finding of this thesis is that negative and positive caregiving experiences were influenced by different factors. A broad range of factors seemed to be related to the caregiving experience of informal caregivers, but not all factors were related to both negative and positive caregiving experiences. Moreover, some factors turned out to be associated to negative and positive caregiving experiences via different pathways. Overall, primary stressors such as a (deteriorating) health situation of the care recipient and the characteristics of the informal care that is provided, and secondary stressors such as the spill-over to other life domains, were related to negative caregiving experiences like subjective caregiver burden. For positive caregiving experiences such as fulfilment from caregiving or self-affirmation, these primary and secondary stressors were less important. Other factors, including relational and attitudinal factors like the quality of the relationship between informal caregiver and care recipient and the intrinsic caregiving motivations of the informal caregiver, were more important for having positive caregiving experiences. In addition, positive and negative caregiving experiences were negatively correlated to each other.
With regard to negative caregiving experiences, we found that a deterioration of the care recipient’s health negatively impacted the informal caregiver’s well-being. When the level of frailty of the older person receiving informal care increased over time (12 months period), and particularly when their psychological well-being deteriorated, informal caregivers experienced a lower care-related quality of life. Informal caregivers especially experienced more often mental and physical health problems due to their caregiving, and more often problems with the combination of informal care with other daily activities. In addition, an increase in the hours of informal care provision over time negatively affected the care-related quality of life of informal caregivers (Chapter 5). Characteristics of the informal care that is provided, including the time investment in caregiving and the complexity of the informal care (i.e., the total hours of informal care provision a week and the number of different informal care tasks that are provided), were also related to negative caregiving experiences, illustrated with a higher subjective caregiver burden (Chapter 6). In addition, informal caregivers dealing with a negative spill-over of caregiving into other life domains such as paid work, social life, or health, also had a more negative caregiving experience (Chapter 6).

For positive caregiving experiences such as fulfilment from informal caregiving, other factors seemed to play a role. We found that caregiving in a high quality relationship between informal caregiver and care recipient and caregiving with high intrinsic caregiving motivations was primarily related to positive caregiving experiences, and not to negative caregiving experiences. Moreover, for informal caregivers who provided long-term informal care (i.e., more years of informal caregiving), relationship quality and intrinsic caregiving motivations may buffer increases in negative caregiving experiences and decreases in positive caregiving experiences (Chapter 6). The time investment in caregiving, including the hours of personal, household, and practical care tasks, and the health situation of the care recipient (i.e., multimorbidity, functional limitations, cognitive functioning) were not related to positive caregiving experiences (Chapter 4). Moreover, changes in the care recipient’s frailty, psychological well-being, and other health domains like functional limitations or social functioning did not affect the level of positive caregiving experiences (i.e., fulfilment and perceived support) (Chapter 5). The spill-over of informal caregiving to other life domains and the characteristics of the informal care that is provided also did not relate to positive caregiving experiences (combined measurement of the positive caregiving aspects ‘outlook on life’ and ‘self-affirmation’) (Chapter 6).

Spousal and adult-child caregivers provide informal care in different care situations
The second main finding of this thesis is that informal caregivers caring for a spouse (spousal caregivers), for a parent or parent in-law (adult-child caregivers), and for another family member, friend, or neighbour (other caregivers)\(^1\), differed on multiple aspects, indicating that they provide informal care in different care situations (Chapter 4, Chapter 6). This is largely in accordance with previous caregiving research (5-9). The differences that emerged in this thesis on socio-demographic

\(^1\) In this thesis, informal caregivers caring for a child (or child in-law) (parental caregivers) were not included, except for Chapter 2 and Chapter 3.
characteristics, the caregiving situation, the health situation of the care recipient, attitudinal and relational factors, and the level of negative and positive caregiving experiences (summarized in Table 1), demonstrate the importance for both caregiving research and policy to take into account the differences between informal caregivers and care situations.

Considering socio-demographic characteristics, spousal caregivers were on average older, more often male, and lower educated than adult-child caregivers and other caregivers. Adult-child caregivers more often had paid work and had a higher self-rated health, compared to spousal caregivers and other caregivers. With regard to the caregiving situation, spousal caregivers provided most hours and number of informal care tasks, compared to adult-child and other caregivers. This difference emerged for the hours of household and personal care tasks; for the hours of practical care tasks and for the duration of caregiving no differences were found between spousal and adult-child caregivers. The differences in the intensity of caregiving (i.e., hours and tasks of informal care) might be explained by the finding that spousal caregivers were also more often living together with their care recipient. When living together, spousal caregivers tend to provide more hours of informal care (6). Adult-child caregivers, in turn, more often cared for a care recipient living in a nursing home or home for the elderly, which is a situation in which care tasks may, in general, be (partly) taken over by staff (10, 11). Adult-child caregivers and other caregivers more often received informal and formal support compared to spousal caregivers.

The health situation of the care recipient also differed between spousal, adult-child, and other caregivers. Care recipients of adult-child caregivers had on average more functional limitations and higher multimorbidity (higher number of chronic and non-chronic diseases or disorders), compared to spousal caregivers. In addition, adult-child caregivers more often cared for a care recipient with cognitive problems or dementia than spousal caregivers. Other caregivers (not spousal, adult-child, and also not parental caregivers) more often cared for a care recipient with behavioural problems, subsequently followed by spousal caregivers and adult-child caregivers. The differences in the health situation of the care recipient are in line with previous research, and may largely be explained by age differences between care recipients of spousal, adult-child and other caregivers (e.g., spousal caregivers caring for younger care recipients than adult-child caregivers and other caregivers) (6).

Considering the attitudinal and relational factors that were studied, no differences were found between spousal, adult-child caregivers and other caregivers in the quality of the relationship with their care recipient, but spousal caregivers had the highest intrinsic caregiving motivation, followed by adult-child caregivers and other caregivers. This corresponds with previous research suggesting that spousal caregivers more often provide informal care because of the strong personal bond with their care recipient, compared to adult-child caregivers and caregivers with another care relation (i.e., other relatives or kin) (5).

With regard to the level of negative caregiving experiences, spousal caregivers seemed to have a more negative caregiving experience, as they had a higher overall caregiver burden, experienced more often mental and physical health problems due to their caregiving, and experienced more often problems with combining informal caregiving with their daily activities, compared to adult-child caregivers. In addition, spousal caregivers also experienced a more disrupted schedule, more financial problems, and
more health problems due to their informal caregiving. Spousal caregivers are older, and therefore might have more difficulties with the provision of informal care, resulting in a more negative caregiving experience and in greater burden on a wide range of areas, compared to adult-child caregivers and other caregivers (6). The presence and strength of the associations of stressors with negative caregiving experiences also varied for the different types of care relationships. For example, spousal caregivers reported relatively more negative caregiving experiences when their care recipient (i.e., their spouse) had more health problems such as cognitive functioning problems or functional limitations, compared to adult-child caregivers. The time investment in informal caregiving did not play a role in the negative caregiving experiences of spousal caregivers, but adult-child caregivers, in turn, had a more negative caregiving experience when they provided more informal care, and particularly more household and personal care, while the health situation of their care recipient was less important for their level of negative caregiving experiences.

Other caregivers had a more overall positive caregiving experience compared to spousal and adult-child caregivers. Other caregivers provided informal care that was lower in intensity (less hours, lower number of different caregiving tasks), which might relate to a more positive caregiving experience. In addition, compared to spousal and adult-child caregivers, other caregivers might be better able to withdraw from informal caregiving and the care situation, and only provide informal care if it brings positive caregiving experiences such as fulfillment or satisfaction. When comparing spousal and adult-child caregivers, we found that spousal caregivers had a more overall positive caregiving experience than adult-child caregivers, which might be explained by the finding in previous research that spousal caregivers more often provided informal care because of the personal bond with the care recipient (5). However, spousal and adult-child caregivers did not differ on their level of fulfillment from caregiving, which is one specific measurement of a positive caregiving experience. Furthermore, no differences were found between spousal and adult-child caregivers in the conditions that relate to positive caregiving experiences.

Spill-over from caregiving to other life domains relates to negative caregiving experiences and results in adaptations at the work place

The third main finding of this thesis concerns the spill-over from caregiving to other life domains such as paid work and social life. Informal caregivers often have multiple other roles besides being informal caregiver, such as parent, sibling, employee, and friend. The provision of informal care can affect and carry over to these other life domains and roles. This spill-over from informal caregiving to other life domains such as work and social life seemed to be associated with negative caregiving experiences, which is in line with other caregiving research (12-18). For example, adult-child caregivers who provided more hours of household and personal care to their parent (in-law), more often experienced problems with other daily activities like household activities, work, study, family, or leisure activities (Chapter 4). Informal caregivers caring for a care recipient whose frailty level increased over time, also had more problems with combining their informal care with other daily activities (Chapter 5). Moreover, when informal caregiving results in a more disrupted schedule, informal caregivers experienced more negative
often they reported they had stopped more than half (56%) had used one or more work arrangement(s)

- giving and the health situation of the care recipient, and secondary stressors

has also been suggested by, for example, the study of Henz and colleagues (19), in which about one

b spousal caregiver more often/higher/longer than adult-child caregiver, adult-child caregiver more often/higher/longer

Table 1: Overview of differences between spousal, adult-child, and other caregivers

<table>
<thead>
<tr>
<th>Socio-demographic characteristics (CG)</th>
<th>Spousal vs. adult-child caregivers (Chapter 4)</th>
<th>Spousal vs. adult-child vs. other caregivers (Chapter 6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Spousal &gt; adult-child</td>
<td>Spousal &gt; adult-child &gt; other</td>
</tr>
<tr>
<td>Female</td>
<td>Adult-child &gt; spousal</td>
<td>Adult-child &gt; other</td>
</tr>
<tr>
<td>Educational level</td>
<td>-</td>
<td>Adult-child/other &gt; spousal</td>
</tr>
<tr>
<td>Paid work (yes)</td>
<td>-</td>
<td>Adult-child &gt; spousal</td>
</tr>
<tr>
<td>Self-rated health</td>
<td>Adult-child &gt; spousal</td>
<td>-</td>
</tr>
<tr>
<td>Caregiving situation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total hours of informal care a week</td>
<td>-</td>
<td>Spousal &gt; adult-child/other</td>
</tr>
<tr>
<td>- Hours of household care tasks</td>
<td>Spousal &gt; adult-child</td>
<td>-</td>
</tr>
<tr>
<td>- Hours of personal care tasks</td>
<td>Spousal &gt; adult-child</td>
<td>-</td>
</tr>
<tr>
<td>- Hours of practical care tasks</td>
<td>No difference</td>
<td>-</td>
</tr>
<tr>
<td>Number of caregiving tasks</td>
<td>-</td>
<td>Spousal &gt; adult-child &gt; other</td>
</tr>
<tr>
<td>Duration of caregiving</td>
<td>-</td>
<td>No difference</td>
</tr>
<tr>
<td>Institutionalized CR (yes)</td>
<td>Adult-child &gt; spousal</td>
<td>-</td>
</tr>
<tr>
<td>Living together with CR (yes)</td>
<td>-</td>
<td>Spousal &gt; adult-child/other</td>
</tr>
<tr>
<td>Informal support (yes)</td>
<td>Adult-child &gt; spousal</td>
<td>Adult-child/other &gt; spousal</td>
</tr>
<tr>
<td>Formal support (yes)</td>
<td>-</td>
<td>Adult-child/other &gt; spousal</td>
</tr>
<tr>
<td>Health situation care recipient (CR)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multimorbidity</td>
<td>Adult-child &gt; spousal</td>
<td>-</td>
</tr>
<tr>
<td>Functional limitations</td>
<td>Adult-child &gt; spousal</td>
<td>-</td>
</tr>
<tr>
<td>Cognitive functioning problems</td>
<td>Adult-child &gt; spousal</td>
<td>-</td>
</tr>
<tr>
<td>(Starting) dementia/cognitive problems (yes)</td>
<td>Adult-child &gt; spousal</td>
<td>Adult-child &gt; spousal &gt; other</td>
</tr>
<tr>
<td>Behavioural problems (yes)</td>
<td>-</td>
<td>Other &gt; spousal &gt; adult-child</td>
</tr>
<tr>
<td>Attitudinal and relational factors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationship quality</td>
<td>-</td>
<td>No difference</td>
</tr>
<tr>
<td>Intrinsic caregiving motivation</td>
<td>-</td>
<td>Spousal &gt; adult-child/other</td>
</tr>
<tr>
<td>Negative caregiving experiences</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall caregiver burden</td>
<td>Spousal &gt; adult-child</td>
<td>Spousal &gt; adult-child/other</td>
</tr>
<tr>
<td>Disrupted schedule</td>
<td>-</td>
<td>Spousal &gt; adult-child/other</td>
</tr>
<tr>
<td>Financial problems</td>
<td>No difference</td>
<td>Spousal &gt; adult-child/other</td>
</tr>
<tr>
<td>Relational problems</td>
<td>No difference</td>
<td>-</td>
</tr>
<tr>
<td>Problems combining daily activities with informal care</td>
<td>Spousal &gt; adult-child</td>
<td>-</td>
</tr>
<tr>
<td>Health problems</td>
<td>-</td>
<td>Spousal &gt; adult-child/other</td>
</tr>
<tr>
<td>- Mental health problems</td>
<td>Spousal &gt; adult-child</td>
<td>-</td>
</tr>
<tr>
<td>- Physical health problems</td>
<td>Spousal &gt; adult-child</td>
<td>-</td>
</tr>
<tr>
<td>Positive caregiving experiences</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall positive experiences b</td>
<td>-</td>
<td>Other &gt; spousal &gt; adult-child</td>
</tr>
<tr>
<td>Fulfilment</td>
<td>No difference</td>
<td>-</td>
</tr>
<tr>
<td>Perceived support</td>
<td>Adult-child &gt; spousal</td>
<td>-</td>
</tr>
</tbody>
</table>

CG = informal caregiver, CR = care recipient, - = not included in study

a Spousal>adult-child = spousal caregiver more often/higher/longer than adult-child caregiver, Spousal>adult-child>other

b Combined measurement of positive caregiving aspects outlook on life and self-affirmation (24)

caregiving experiences (i.e., a higher caregiver burden) (Chapter 6).

Caregiving-to-work spill-over may result in adaptations at the work place, in order to continue informal caregiving. This indicates that informal caregiving can affect working life trajectories, which has also been suggested by, for example, the study of Henz and colleagues (19), in which about one third of informal caregivers of a sick, disabled or elderly person reported one or several effects of their
informal care provision on their working life trajectory. Most often they reported they had stopped working (19). In our sample of 333 adult-child informal caregivers who combined informal care with paid work, more than half (56%) had used one or more work arrangement(s) (Chapter 7). This included taking time off (41%), making individual agreements with their supervisor (e.g., flexible working hours, working (more) from home) (30%), formal care leave arrangements (e.g., short-term care leave, long-term care leave, emergency leave, special leave, or unpaid leave) (15%) and a reduction of paid working hours (6%). In case working adult-child caregivers faced many responsibilities, such as high care demands (i.e., more different types of informal care tasks, more hours of informal care provision), experienced more often health problems or a disrupted schedule due to caregiving, or had long working hours, they had adapted their work situation more often. The level of positive caregiving experiences (caregiver self-esteem) was not related to the use of one or more work arrangements (Chapter 7).

IMPLICATIONS OF RESEARCH FINDINGS

Enhancing positive caregiving experiences in caregiver interventions

The results presented in this thesis with regard to the conditions related to negative caregiving experiences are in line with existing caregiving research (13, 18, 20-22) and the caregiving stress process model of Pearlin and colleagues (23). They affirm once again that primary stressors such as the time investment in caregiving and the health situation of the care recipient, and secondary stressors like the spill-over of informal caregiving to other life domains, have a negative impact on informal caregiver’s caregiving experiences, including high subjective caregiver burden and low care-related quality of life.

For policy and the development of caregiver support interventions, a perhaps more important conclusion is that the level of positive caregiving experiences (e.g., fulfilment from caregiving, positive outlook on life, self-affirmation) is not related to primary and secondary stressors, but mainly to other factors such as the quality of the relationship between informal caregiver and care recipient and the level of intrinsic caregiving motivations. This is in line with previous caregiving research showing that positive and negative caregiving experiences are affected by primary and secondary stressors in different ways (5, 25-27). This has important implications for caregiver support interventions, because the results suggest that the factors included in caregiver interventions in which negative caregiving experiences are successfully addressed, do not have to be the factors that can successfully increase positive caregiving experiences as well. Currently, caregiver support interventions often focus on alleviating negative caregiving outcomes, such as subjective burden, stress, depression, or anxiety (28, 29), and many different types or forms of caregiver interventions exist, like psychoeducational interventions, cognitive behavioural therapy, counselling or case management, respite care, training for the care recipient, physical activity interventions, or general support (28, 30). These different types of interventions vary in their effects on negative caregiving outcomes, and not all approaches affect all
The type of care relationship in caregiver support and interventions

The impact of the hours of informal care provision differs between spousal and adult-child caregivers, as described earlier (see main research findings). This emphasizes the importance of why the type of care relationship should be incorporated in the development and provision of effective caregiver support. Not all types of support may be beneficial to all informal caregivers. Considering the example of time investment in caregiving, adult-child caregivers may benefit from a reduction in caregiving tasks or responsibilities, because they often combine informal caregiving with other activities and responsibilities (32). A lower time investment in caregiving might thus reduce their negative caregiving experiences. However, as suggested in previous research, a lower time investment may also decrease their level of positive caregiving experiences (5), which is not desirable. Adult-child caregivers may be best of with support related to their other activities and responsibilities as well, such as child care, help with their own household chores, or support in finding a balance between paid work and informal care, if necessary. In contrast to adult-child caregivers, spousal caregivers often live together with their spouse, and are almost constantly confronted with the problematic health situation of their beloved one (22). This thesis showed that the health situation of the care recipient was especially important for the level of negative caregiving experiences among spousal caregivers (Chapter 4). Therefore, spousal caregivers may particularly benefit from learning how to deal with the worry and anxiety related to the health situation of their loved one. Moreover, enabling them to clear their head now and then, for example by arranging respite care, might be helpful.
Information about formal care leave arrangements

In our study, almost half of the working adult-child caregivers had taken time off to provide informal care (Chapter 7). Taking time off for informal care provision reduces the possibility to take time off for themselves, for relaxation, social activities, leisure activities or holiday. From this perspective, the use of a formal care leave arrangement might be a better option, because this does not affect the number of free days available to take off. However, in our sample of working adult-child caregivers only 15% had used one or more formal care leave arrangements (mainly short-term care leave, emergency leave, special leave, or unpaid leave) (Chapter 7). One explanation could be that not all working informal caregivers are in need of formal care leave, for example when they provide informal care in a care situation that is low in intensity or when they experience low burden. However, working informal caregivers may also be unaware of their options to use formal care leave arrangements (33, 34).

Not taking up formal care leave may also have other reasons. In a study of The Netherlands Institute of Social Research almost 20% of the working informal caregivers said they needed, but did not take, long-term care leave (34). For short-term care leave, this discrepancy between the use of and the demand for (short-term) care leave was around 12% (34). The main reasons mentioned by working caregivers who did not use short- or long-term care leave even though they were in need for it, were that they did not want to impose on their colleagues or that their work did not allow them to take up short or long-term care leave. Financial consequences of taking formal care leave turned out to be less important (34). This is remarkable, especially for long-term care leave, as this is unpaid (payment during short-term care leave in the Netherlands is at least 70% of the salary). The financial situation and consequences thus seemed to be a smaller impediment for taking formal care leave than the situation at work (34).

In the near future, a growing number of people will combine paid work with informal care tasks (2). Therefore, working informal caregivers need to be supported in their combination of work and care tasks, if necessary. To raise the awareness of the possibilities of formal care leave, working informal caregivers need to be provided with information about their options. In addition, working informal caregivers who are in need of formal care leave but do not use it because of impediments at work, should be stimulated to discuss their situation with employers, supervisors and colleagues. Initiatives like the Dutch ‘Work&Informal Care Recognition’ (Werk&Mantelzorg Erkenning; https://www.werkenmantelzorg.nl) are a good example of how the awareness and recognition of the problems that working informal caregivers may face can be increased within organizations and companies and among employers and colleagues of working informal caregivers. Moreover, employers are stimulated to provide information about formal care leave arrangements to their employees and to offer flexible and tailored solutions that fit individual working informal caregivers. In addition, a related platform for working informal caregivers themselves (M-power platform, https://www.mantelzorgpower.nl) provides information about care leave arrangements and other formal regulations, tools and tips and tricks about finding and maintaining a balance between work, informal care and family, and information about how to discuss problems and solutions with supervisor and colleagues. All aimed at reducing and preventing the burden and stress that may arise from
problems with combining paid work with informal care, which contributes to a sustainable employability of working informal caregivers.

In this thesis, it is suggested that particularly lower educated working adult-child caregivers are less likely to use a formal care leave arrangement (Chapter 7). A possible explanation could be that lower educated working caregivers are more often unaware of their options. In that case, specific attention should be paid to lower educated working caregivers when informing working caregivers about the availability of taking up care leave. However, other explanations may exist as well. People with a low educational level generally have a lower earning capacity, with a lower household income (35). As a result, lower educated working caregivers may be less able to accommodate the financial consequences that might exist when taking up formal care leave, compared to higher educated working caregivers with a higher household income (34). The use of formal care leave might also be better organised or more accepted in better paid jobs (34). Furthermore, lower educated people more often have jobs with a lower job security, with, for example, more often a flexible or temporary instead of a permanent contract (35). With a lower job security, working caregivers might be more afraid to lose their job, which may impede arranging, asking and taking up formal care leave. In addition, lower educated working caregivers may be more likely to have a job in which their physical presence is required, with few options to work from home or from another location, or to work at other times, like the services sector (e.g., hospitality industry, catering industry), construction industry (e.g., construction workers, manufacturers) or transport industry. When physical presence is required, this could make it more difficult to arrange, manage, ask and use formal care leave arrangements if necessary. A study among working caregivers who cared for a sick, disabled or elderly person found that semi-routine manual workers (e.g., postal workers, machine operatives, farm workers, catering assistants, sales assistants) and routine manual workers (e.g., cleaners, labourers, waiters/waitresses, bar staff, sewing machinists, truck drivers) reported the strongest negative effects of their informal care provision on their work situation (i.e., reduced working hours or stopped working), compared to working caregivers in managerial and professional occupations, small employers and own account workers, and lower supervisory and technical occupations (19).

METHODOLOGICAL CONSIDERATIONS

Complexity in informal care research
Studying informal caregiving and negative and positive caregiving experiences turned out to be complex, as many different factors play a role and can be related to each other as well. Which factors relate to negative and positive caregiving experiences 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, sample sizes were not always large enough to perform the intended statistical analyses and studies could have been underpowered, despite that there were 965 informal caregivers participating in Lifelines ICAS. For example, in Chapter 7, we used a selection of 333 working adult-child informal caregivers,
and we were not able to conduct multivariate logistic regression analyses for the four different work arrangements under study. More specific, for the individual agreements with the supervisor, the formal care leave arrangements, and the reduction of paid working hours, the number of events per variable (EPV) was lower than 10, which may influence the validity of the multivariate logistic model (36, 37). Therefore, only univariate logistic regression analyses could be conducted, without being able to control for relevant background characteristics and/or potential confounding factors, such as the total hours of informal care provision a week, the experience of a disrupted schedule or health problems due to caregiving, or the hours of paid work a week.

Future caregiving research needs to invest in achieving sample sizes that are large enough to be able to answer the research questions of main interest. In addition, researchers need to consider whether they focus on a selection of informal caregivers, such as spousal caregivers caring for a partner with psychological problems or high levels of frailty, or working adult-child caregivers who combine their informal care tasks with multiple other tasks and roles. This decision has consequences for the composition of the intended study sample and the recruitment of potential participants. With a focus on informal caregivers who care for a person with a specific diagnosis, for example Alzheimer’s disease or stroke, informal caregivers are often recruited via their care recipient (indirect recruitment). For example, Buchanan and colleagues (38) studied informal caregivers of people with multiple sclerosis, and contacted these informal caregivers via people who participated in a registry of multiple sclerosis patients. Recruitment of participants can also be based on, for example, the type of care relationship or other roles or responsibilities of the informal caregiver (e.g., working caregivers). In these situations, a direct recruitment of informal caregivers might work better (see for example (39)), with a primary focus in the recruitment procedure on characteristics of the informal caregiver instead of care recipient.

Relevant factors are missing
Related to the complexity of factors being associated to negative and positive caregiving experiences, it proved to be difficult, or even impossible, to include all relevant factors in the questionnaire and statistical analyses. In order to limit the burden for research participants in the Lifelines Cohort Study and Lifelines ICAS, we had to make choices in the topics and questions we included in the survey questionnaire (see Chapter 2 for a detailed description of the topics included in the Lifelines Cohort Study and Lifelines ICAS). For example, topics like coping strategies (40), the cooperation with professional healthcare providers (41), the cooperation and sharing of informal caregiving responsibilities within informal care networks (42), or personality traits (43), were not included in the survey questionnaire, but can be relevant for the level of negative and positive caregiving experiences. Inclusion of one or more of these topics would have led to a longer questionnaire, which could have resulted in a lower response of research participants. In Lifelines ICAS, the response rate was 48% and selection based on the level of caregiving involvement occurred. This selection also slightly affected the direction and magnitude of associations of some caregiving stressors with caregiver burden (Chapter 3). In caregiving research, large differences between response rates exist, with response rates varying from 31% (44) to 81-96% (45). Due to differences in selection criteria, recruitment methods, and also
the content of research projects, comparing study populations and response rates between caregiving studies is difficult (46).

**Nonconsent and nonresponse bias**

With regard to research participation, nonresponse might be higher among informal caregivers than among people not being informal caregivers (47), but little is known about whether and which characteristics of informal caregiving relate to nonconsent and nonresponse in caregiving research, mainly due to a lack of information about nonrespondents (48, 49). In this thesis, information was collected about the Lifelines participants who indicated to provide informal care but did not participate in Lifelines ICAS (Chapter 2 and Chapter 3). Participation in caregiving research was not evenly distributed among informal caregivers. Particularly informal caregivers who were highly involved in their caregiving (i.e., high time investment and high caregiver burden) were more likely to consent to, and participate in, Lifelines ICAS (Chapter 3). This suggests that a high time involvement and high caregiver burden is not so much a constraint for research participation (50–52), but that individuals may be even more inclined to participate in research when the topic is highly relevant to their own lives (53, 54), in this case their role as informal caregiver. The level of caregiving involvement also turned out to be important for the associations with caregiver burden, since the associations between some indicators of caregiving involvement (i.e., time investment in caregiving, duration (in years) of caregiving) with caregiver burden were more evident among consent and response caregivers than among nonconsent and nonresponse caregivers (Chapter 3).

Researchers need to take the possibility of nonconsent and nonresponse bias into account, as some associations with caregiver burden might be overestimated. Attempts to increase research participation, such as sending (multiple) reminders for research participation, can be an effective way to increase response rates (55, 56). However, higher response rates do not guarantee a lower nonresponse bias (48, 57). Therefore, next to the option to apply strategies to increase research participation and response rates, the collection of additional information about nonconsent and nonresponse caregivers should be default in each caregiving study. This facilitates a better understanding of the impact of nonconsent and nonresponse on the study results for each specific study.

The definition of informal care that is used and how informal care is explained to potential participants (i.e., broad or strict definition; inclusion of the term 'informal care' or not) should also be a point of attention. A study on the barriers of identifying informal caregivers of people with advanced illness in primary care, showed that informal caregivers often prefer to think of themselves in relational terms to their care recipient (e.g., their spouse, parent (in-law), other relative, or friend), and that they do not immediately identify themselves as ‘informal caregiver’ (58). This suggests that informal caregivers who are (more) aware of their role as informal caregiver might be more likely to identify themselves as informal caregiver and to consider themselves as belonging to the target population of the study.
DIRECTIONS FOR FUTURE RESEARCH

The identification, incorporation and evaluation of factors that enhance positive caregiving experiences in caregiver interventions

In this thesis, we focused on the quality of the relationship between informal caregiver and care recipient and the level of intrinsic caregiving motivations, and demonstrated the importance of these relational and attitudinal factors for positive caregiving experiences. However, these factors only explained 18% of the variation in positive caregiving experiences, suggesting that there are also other factors that we did not study that affect the experience of positive aspects of caregiving. For example, religion (59, 60) and specific caregiving strategies like problem focused coping (25), active management (61), and encouragement (26), all affected the level of positive caregiving experiences. For future caregiving research, the challenge is to identify what (other) resources are needed to enhance positive caregiving experiences, to evaluate how these resources can be incorporated into caregiver interventions aimed at enhancing positive caregiving experiences, and to study the actual effects of caregiver interventions on the positive aspects of caregiving (62). In this process, a distinction might be helpful between internal (i.e., characteristics within the individual, like self-efficacy, coping, or health) and external (i.e., factors outside the individual, like social support or financial support) resources (63). External resources may be better suitable for change, and easier to address in caregiving interventions than internal resources. In addition, the improvement of external resources such as the social network within which informal care is provided or an employer’s attitude towards caregiving employees, may require a different approach or type of intervention than the improvement of internal resources like the level of personal control or the informal caregiver’s perseverance.

Taking the type of care relationship into account

The results in this thesis with regard to the differences between spousal, adult-child and other caregivers, emphasize the importance of taking the type of care relationship into account in caregiving research. For the study of positive caregiving experiences, future caregiving research should recognize and evaluate the possible differences between spousal, adult-child, and other caregivers, since the majority of studies does not differ between these types of care relationship (63). In this thesis, differences in the level of positive caregiving experiences emerged between spousal, adult-child, and other informal caregivers, but no differences in the conditions related to positive caregiving experiences were found. There are, however, other caregiving studies in which it is suggested that differences in these conditions exist (5, 26, 27, 63). For example, a study among Dutch informal caregivers providing care to a person over the age of 64 in a wide range of care situations (e.g., one or more chronic diseases, temporarily ill, dying), found that adult-child caregivers who provided more hours of informal care a week had a more positive caregiving experience, while for spousal caregivers the hours of informal care provision did not relate to their level of positive caregiving experiences. In addition, adult-child caregivers who provided more hours of informal care a week also had a higher caregiver burden, which again was not found for spousal caregivers (5). This was confirmed by the study described in this
thesis (Chapter 4). In addition to the study of Broese van Groenou and colleagues (5), in which the total hours of informal care provision a week was studied, the results described in this thesis suggest that particularly the provision of more personal care is associated to more negative caregiving experiences among adult-child caregivers (Chapter 4). These results suggest that for adult-child caregivers, the amount of informal care provision may be considered as an indication of how much they are involved in and affected by their informal caregiving, both positively and negatively. In contrast, for spousal caregivers, other aspects might be more relevant, such as the health situation of their spouse, because they more often are living together with their spouse and are almost constantly confronted with the (deteriorating) health problems of their spouse (22). In addition, also the age of the spousal caregiver might play a role in how they experience their informal caregiving. Spousal caregivers are often older compared to adult-child caregivers, and also have more often health problems, which could affect how they experience their informal caregiving (6).

The ‘sense of entitlement’ to use formal care leave arrangements
Characteristics of the work situation, like job type and the attitude and opinion of organizations, companies, supervisor and colleagues with regard to combining paid work with informal care tasks, may influence whether and to what extent working informal caregivers feel entitled to take formal care leave (their ‘sense of entitlement’) (34). Therefore, for future caregiving research the influence of work characteristics such as job type and the role of organizations or companies, both on organizational, team, and supervisor level on this ‘sense of entitlement’ is an important study topic. In addition, an interesting and relevant question to answer is whether working informal caregivers would more often use long-term care leave when financial consequences are smaller, for example when payment during long-term care leave would be 70% of the salary, comparable to short-term care leave. These insights are needed for government and policy makers to be able to make well-argued decisions about possible changes in leave arrangements and other forms of support at the workplace, in order to strengthen the position of working informal caregivers and to enable them to remain active in both paid work and informal care.

Informal caregiving is dynamic: longitudinal studies are needed
Most caregiving studies are cross-sectional, studying a snapshot of the informal care situation and the caregiving experience (5, 63). However, informal caregiving is not static, and the informal care situation, positive and negative caregiving experiences, and aspects such as the health situation of the care recipient, care needs, available support, or employment situation, are continuously subject to change. For instance, research has shown that the perceived stress of informal caregivers is affected by transitions in caregiving status and changes in the intensity of informal caregiving (64), that increases in the number of hours of informal care provision a week predicted the level of caregiver gains over time (27), and that coping, caregiver appraisal, and caregiver reappraisal fluctuate over time (65). The results of the studies described in this thesis (Chapter 4 and Chapter 5) also showed that the caregiving situation and caregiving experiences at one point in time affect caregiving experiences at a
later time point. It illustrates the importance of longitudinal caregiving studies in which caregiving trajectories, the conditions leading to negative and positive caregiving experiences, and possible interactions between characteristics of the caregiving situation, are evaluated.

Researchers conducting longitudinal caregiving studies should invest in the prevention of drop-out of care recipients and informal caregivers during their study, as drop-out can introduce selection bias and affect study results. Keeping contact details up-to-date, sending one or more reminders for participation, (non-)monetary incentives, sending out newsletters regularly in between measurements, and emphasizing in all correspondence to the participants that their participation is important and that their contribution to the study is valuable and vital for future informal caregivers, are options to prevent drop-out of research participants (55, 66). However, drop-out can never be completely prevented, because there are reasons for drop-out that cannot be avoided, like the death of the care recipient (or informal caregiver) or a move to a region outside the study region. This makes it essential to collect information about participants who drop out of the study, and why they drop out of the study, so that it can be estimated if and how this affected the study results.

**Large sample sizes and well-thought selection of topics**

Due to the complexity in caregiving research, large sample sizes are required to be able to answer specific research questions concerning specific groups of informal caregivers. It allows the study of subgroups of informal caregivers, like working adult-child caregivers who combine multiple roles, or spousal caregivers caring for a spouse with deteriorating psychological well-being. One possibility to obtain large sample sizes could be to combine data from multiple studies. This requires the use of one survey questionnaire with the same topics and questions in multiple studies, so that data can be combined and compared across studies. A good example of such an initiative is The Older Persons and Informal Caregivers Survey Minimum DataSet (TOPICS-MDS) (67) (see also Chapter 5). All participating research projects collected information of older persons and, if applicable, their informal caregivers. A standardized questionnaire (Minimum DataSet) was developed, and included questions on older person’s demographics, morbidity, quality of life, functional limitations, mental health, social functioning and health service utilisation. With a separate questionnaire for informal caregivers, information was collected on their demographics, hours of informal care provision and quality of life (including a measure of subjective care-related burden).

TOPICS-MDS is a good step in the right direction for the study of caregiving experiences, but this thesis also suggests that many more factors are important for the caregiving experience. Therefore, initiatives such as a TOPICS-MDS should be continued, and if possible enriched with more information (e.g., indicators of spill-over to other life domains, coping strategies, availability and use of formal and informal support). One interesting option to enrich data collected in initiatives such as a TOPICS-MDS, without increasing the burden on participating informal caregivers, are linkages with other data sources, such as health registries, death registries or environmental data from Statistics Netherlands. Another option would be to collect more information among informal caregivers and care recipients. Because the burden that is placed on participating informal caregivers needs to be taken into account, this
Chapter 8

requires a well-thought selection of topics and questions. Based on the results described in this thesis, an example of a relevant topic to include is the quality of the relationship between the informal caregiver and care recipient. Questions concerning mechanisms that may explain how relationships between informal caregiver and care recipient change during informal caregiving can provide the necessary insights for caregiver interventions aimed at enhancing positive caregiving experiences and alleviating negative caregiving experiences. One possible mechanisms could be the level of gratitude expressed within caregiving couples. For healthy married couples, gratitude plays a role in maintaining close relationships (68), and gratitude is often present in caregiving dyads as well (69, 70). The expression of gratitude by the care recipient may maintain or improve the quality of the relationship, and may also lead to a more positive caregiving experience for the informal caregiver.

CONCLUDING REMARKS

This thesis illustrates that variation in negative and positive caregiving experiences of informal caregivers is explained by a variety of factors. Caregiving stressors such as caregiving intensity and spill-over to other life domains mainly explain variation in negative caregiving experiences, while relational and attitudinal factors explain variation in positive caregiving experiences. In addition, caregiving experiences can differ between groups, for example between spousal, adult-child, and other caregivers, and working informal caregivers may need to adapt their work situation to continue both paid work and informal care. This is essential for (the development of) effective caregiver support and for prioritizing areas for policy action, in order to support the growing number of informal caregivers that are facing increasing demands and expectations.
General discussion

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General discussion
