Sharing the care of older parents
Tolkacheva, N.

2011

document version
Publisher's PDF, also known as Version of record

Link to publication in VU Research Portal

citation for published version (APA)

General rights
Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

• Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
• You may not further distribute the material or use it for any profit-making activity or commercial gain
• You may freely distribute the URL identifying the publication in the public portal

Take down policy
If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

E-mail address:
vuresearchportal.ub@vu.nl
CHAPTER 1

General Introduction
Given population aging and the shift toward community-based care, informal care for frail older people has become a critical policy issue. Professional care is far more expensive than informal care, leading politicians to stress the individual responsibility of civilians to take care of their relatives, friends and neighbors. In the Netherlands, 75% of community-based care is provided by informal caregivers and 25% is provided by professional caregivers (VWS, 2001). In 2007, about 61% of Dutch informal caregivers provided care for more than eight hours per week and had done so, on average, for five years (Hoefman, 2009). Informal care to older adults has been widely studied in the literature on caregiving. Authors have used a variety of terminology in these studies, referring to care, support, help or assistance (see, e.g., Davey & Szinovacz, 2008; Silverstein, Conroy, & Gans, 2008). Though the difference between these terms is not explicitly defined, many understand care to mean help with daily activities, such as aiding with personal tasks or climbing stairs, whereas support may include less specific tasks, such as help with financial issues or visiting. The reader of this thesis should bear in mind that although in most cases I will use the term care, I do not make a strict distinction between these terms, and this research involves a broad spectrum of activities carried out by adult children to care for and support their parents.

After spouses, children are the main source of informal care for older adults. Various demographic trends suggest that parental needs for informal care increase and that children’s support to their old parents becomes an important societal issue. Due to longer life expectancy for parents and longer periods of chronic illness in later life, many adult children are confronted with their parents’ physical or mental impairment for a considerable length of time. Rising elderly divorce rates increase the likelihood of a lack of spousal support for a frail parent, emphasizing children’s caregiving responsibilities. Additionally, growing numbers of aging couples with physical or cognitive impairments mean that children may need to care for both of their parents. At the same time, female participation in the labor force, postponed fertility, and caring for young children at an older age means that adult children must fulfill various roles and responsibilities simultaneously, and they may run the risk of overburdening themselves. In the future, such pressure on children is likely to increase. Due to decreasing fertility rates, future generations will be smaller, meaning that fewer potential caregivers will be available to support older adults. Given the expanding support needs, higher demands and larger variety of children’s roles, it is important that care be shared among multiple caregivers.
There is a range of possibilities for children to share support with others, and adult children do not have to respond to parental needs on their own. The children of older adults belonging to a baby boom cohort are likely to have multiple siblings. Children also have other potential ways to share their caregiving responsibilities, such as their spouses, other relatives, friends or neighbors (Broese van Groenou & Van Tilburg, 2007; Szinovacz & Davey, 2008). However, little is known about multiple caregivers. Over the past decades, literature on filial caregiving has paid considerable attention to parent-child dyads, specifically adult children becoming caregivers for their parents (e.g., Dautzenberg et al., 2000; Lawton, Silverstein, & Bengtson, 1994; Parrot & Bengtson, 1999). Most studies on filial caregiving have focused on the primary care-providing child. However, dyadic studies are not always sufficient to understand the nature of family caregiving. A number of studies have examined how families make use of multiple caregivers (Dilworth-Anderson, Williams, & Cooper, 1999; De Boer, 2003; Keith, 1995) or have provided evidence of various aspects of sibling interaction in family care (Finch & Mason, 1990; Ingersoll-Dayton, Neal, Ha, & Hammer, 2003; Matthews, 1987; Matthews, 2002; Silverstein et al., 2008; Spitze & Logan, 1990; Wolf, Freedman, & Soldo, 1997). Still, there is limited research on children as caregivers, which considers the presence of their siblings or other kin and non-kin, and therefore takes into account children’s embedding in the context of broader kinship or non-kinship networks. In addition to previous research focusing on the individual child, this thesis expands knowledge by considering filial caregiving in relation to other potential and existing caregivers. The aim of the dissertation is twofold: to describe the various caregiving contexts in families of older adults, and to examine the antecedents and consequences of children’s caregiving when other potential and existing caregivers are taken into account.

Theoretical Background: Model of Caregiving

A number of models of parent-child caregiving are discussed in the literature. One of the most widely used paradigms in family caregiving is the intergenerational solidarity framework, consisting of six dimensions in which family integration between generations occurs (Bengtson & Roberts, 1991). The associational and affectual dimensions of solidarity describe the contact and positive emotions among family members, respectively. The structural dimension refers to the structures that provide or restrict opportunities for interaction between generations.
The consensual and normative dimensions of solidarity represent attitudes about the centrality and importance of the family and values surrounding the enactment of help and support norms among family members. The functional dimension reflects the extent to which help and support is exchanged. Although the model focuses on solidarity between generations in a broader sense, previous caregiving research has often applied it to explanations of caregiving processes by considering the associational, affectual, structural, consensual and normative dimensions as predictors of the functional dimension. The application of this framework mostly refers to vertical dyadic relationships between generations, particularly the parent-child dyad. It is however unclear how the model would function when children are embedded in broader kinship and non-kinship networks.

Another framework applied in various caregiving studies is the stress process model (Pearlin, Mullan, Semple, & Skaff, 1990). The model links the psychological and physical well-being of caregivers with the number of stressors in the caregiving situation, such as parental needs, caregiver role strains (for example, employment outside the home) and coping mechanisms (for example, mastery). In modifications to this framework by others (e.g., Yates, Tennstedt, & Chang, 1999), the concept of appraisal is added to the framework, emphasizing subjective aspects such as evaluation of the caregiving situation. Although the stress process model specifically focuses on caregiving and stress that caregivers experience, and uses a different terminology than the intergenerational solidarity model, some determinants of caregiving are similar in both frameworks. As an intergenerational solidarity model, this framework emphasizes dyadic caregiver-recipient relations, but it does not offer an explanation about the mechanism of the stress process if multiple caregivers are taken into account.

The current dissertation looks at a general model of caregiving (see Figure 1.1) that combines elements of both the intergenerational solidarity and stress process models. The framework departs from a number of general arguments explaining whether and to what extent a child provides care to his or her parent (Broese van Groenou, 2005). Furthermore, caregiving is linked to one of its outcomes: children’s assessment of and feelings about the caregiving situation (the caregiving burden). The innovative element “OTHERS” is added to the model in order to reflect the embedding of children in broader networks of other potential and existing caregivers.
Much is known about some parts of the model. Determinants of caregiving have been widely discussed in previous research on parent-child dyads. The amount of caregiving by children is dependent on the degree of parental physical and cognitive impairment, the specific demands placed on children, and the type and amount of care needed by parents (Soldo, Wolf, & Agree, 1990). Children’s individual characteristics are important predictors of whether and to what extent children are involved in caregiving. Daughters often provide more care than sons do (Silverstein, Parrott, & Bengtson, 1995). Structural characteristics, reflecting children’s time constraints, are associated with the amount of caregiving; for example, children who are geographically proximate, unemployed or unmarried provide the most support to their parent (Dautzenberg et al., 2000; Dwyer & Coward, 1992; Silverstein et al., 2008). Further, affectual characteristics, such as being emotionally close to a parent, are important determinants of the amount of support (Lawton et al., 1994). Normative characteristics play a significant role in parental support as well. It has been demonstrated that children’s strong norms of filial obligation increase the likelihood of care provision (Campbell & Martin-Matthews, 2003; Silverstein et al., 2008). Strong filial expectations by parents are associated with greater support provision by children (Klein Ikkink, Van Tilburg, & Knipscheer, 1999). Another part of the model represents the outcomes of caregiving. The link between caregiving and the caregiver’s burden or overload has been broadly discussed in studies investigating the caregiver’s burden and psychological and physiological well-being (e.g. Chappell & Reid, 2002; Dwyer, Lee, & Jankowski 1994; Pearlin et al., 1990; Yates et al., 1999). The caregiver’s burden increases by greater severity of parental needs for care and by the amount of care provided by children. Most of the research listed above has looked at caregiving from the dyadic perspective of an individual caregiver and care recipient.
In the current dissertation, I look beyond the caregiving dyad and call attention to the familial context of caregiving and to existing or potential opportunities for children to share care. The role of “OTHERS”, indicated in Figure 1.1, is central to this research and innovative within the existing literature. I only consider families with potential and available “others”, where caregiving can be shared. It is presumed that even non-caregiving family members can influence caregiving children and their decisions because family members are not isolated from one another and a certain level of interaction can be assumed. Different family contexts are taken into account: families with multiple children, families with both sibling genders, and families where children share care within kinship or non-kinship caregiving networks. In this dissertation, the influence of others is seen from different angles: from the perspective of sibling solidarity and joint care for the parent, from the perspective of equity and sharing, from the perspective of gender equality and from the perspective of caregiving network and its impact on the individual. The dissertation contributes to the existing literature on filial caregiving by a) explaining individual care provisions by considering sibling care decisions and characteristics; b) adopting a family perspective and describing the division of care activities among all children of physically impaired older parents; c) addressing gender differences in caregiving in the context of gender role ideology and changes between cohorts; and d) considering sharing care in broader caregiving networks in relation to the adult child’s caregiver burden. Four research questions are addressed in this book. They are discussed in more detail in the following four chapters.

Research Questions

The first research question is: To what extent is the individual child’s caregiving affected by the caregiving of the child’s siblings, the gender composition of a sibling group and the siblings’ characteristics?

This research question goes beyond individual caregiving by taking into account the potential influence of the sibling network on a child’s caregiving behavior. This approach builds upon previously investigated determinants of caregiving related to the parental need for assistance and the child’s individual characteristics. Two possible scenarios of children’s caregiving are considered. First, one can expect that siblings agree that caring for their parent is a family
affair in which more than one child should take part. In this case, the children regard their caregiving responsibilities jointly with their siblings. This case reveals a sense of sibling solidarity. In another scenario, a child could provide no or less assistance because the other siblings are doing the job. This occurs due to “free-riding” or “self-interest”; a child might refrain from caregiving if he or she knows that siblings are providing care. Furthermore, relativity in siblings’ characteristics is investigated. For instance, an individual child’s travel distance to a parent does not reveal much about the amount of care unless the travel distance of his or her siblings is taken into account. Living far away from a parent does not necessarily mean that a child provides little or no care to a parent if the other siblings live even further. Therefore, I look at how conducive to caregiving the child and siblings’ characteristics are.

The second research question is: To what extent and how equally is the care shared in multiple child families, and to what extent do similarities among sibling characteristics influence the sharing of care among siblings?

This research question raises issues of sharing the care among siblings and the equality in the intensity of the distribution of caregiving from the family perspective. It reflects the link between parents and children’s individual characteristics and children’s caregiving when all of the children’s characteristics and caregiving are aggregated to the family level. I investigate which families are most likely to achieve equality in sharing the care considering the similarities among siblings’ characteristics and their caregiving behavior. The idea of similarity is reflected in the argument derived from social psychology stating that people who share values and status have rewarding interactions and are attracted to each other (Homans, 1974). Mutual attraction, in turn, may result in mutual responsibilities regarding parental support.

The first and second research questions are addressed by using data collected in the context of the study “Family Caregivers of Older Adults”, a side study of the Longitudinal Aging Study Amsterdam (LASA). LASA is an ongoing study on the physical, social, cognitive and psychological functioning of older Dutch adults. The main data collection of LASA consisted of three annual interviews with a representative sample of 3107 Dutch older adults aged 55-85 years at baseline in 1992. In each cycle, data were collected on physical and
mental health, receipt of professional and informal care and the exchange of support with children and other personal network members (among other topics). The data collection for the side study on family caregivers was conducted in the year 2000 between two cycles of the main data collection for LASA (1998/1999 and 2001/2002) (Broese van Groenou, Deeg & Van der Horst, 2001). The sample for the side study was selected from the respondents in the 1998/1999 cycle (N=2,076) by means of six criteria (Knipscheer & Broese van Groenou, 2004) that left 316 respondents to be approached for participation in the side study. The most important criteria were that the respondent had living children, was functionally disabled and suffered from at least one chronic disease, and received care from an informal and/or a formal source. Of the 316 respondents selected, 256 parents participated in the side study. The face-to-face interview covered topics including health, use of care, and psychosocial characteristics. The respondents reported on the characteristics and care activities of all their children (N = 914, range 1-15, average 3.6 per parent). Care activities included the frequency of assisting with five domestic care activities and five personal care activities.

The third research question of this dissertation is: *To what extent does the degree of egalitarianism of gender role ideology explain gender differences in parental support, and does the explanatory model of support taking into account gender role ideology change between 1988 and 2000?*

This question refers to gender inequalities in parental support. This chapter reflects the idea of male potential for caregiving. I highlight the importance of gender norms for both daughters and sons when studying support to aging parents. In addition, I acknowledge changes in personal and familial contexts over time (e.g., increasing employment by women, changes in norms) as well as changes in supportive behavior between children and parents (Van der Pas, Van Tilburg, & Knipscheer, 2007). I look at changes in gender roles in historical context and their implications for possible changes in gender inequality. Daughters provide most of the support to their parents, but at the same time, they are increasingly participating in the labor force and getting better educations. Therefore, borders between typically “male” and typically “female” behavior begin to fade, eventually resulting in increasing egalitarianism in gender role ideology. This may affect caregiving in families with siblings of both genders.
The third research question is addressed by using data from the Longitudinal Study of Generations (LSOG), a study of 2044 individuals aged 16 to 91 from 328 three- and four-generation families. The study began in 1971, with a sample of older male adults and their spouses who were randomly selected from the members of a large (840000-member) prepaid health maintenance organization in the Los Angeles area. Individuals aged 55 years or older with at least one grandchild aged 16 or older were eligible for inclusion. The sample pool generally represented white, working-class and middle-class families. The questionnaires were mailed to selected individuals, their spouses and their descendants aged 16 years or older. An overall response rate of 70% was achieved. Since 1985, the sample members have been surveyed again, and data collection has been repeated at three-year intervals. Members of each generation reported on their cross-generational and marital relationships, sociopolitical opinions, values, health, psychological well-being, and economic and occupational status (Silverstein et al., 1995; Silverstein et al., 2008).

The fourth research question of this dissertation is: To what extent does sharing care with a larger caregiving network reduce an individual child's caregiver burden?

This question concerns a negative outcome for caregivers, particularly the caregiver burden experienced by a child. I look at adult child caregivers sharing care within broader caregiving networks and investigate the link between caregiving activities by a child and other caregivers and a child's caregiving burden. Networks of social relationships are considered as potential sources of social, emotional and practical support. I depart from the idea that social contact and positive interactions enhance individuals' well-being by providing them with a sense of security and a potential support base. Interactions within a network can also be negative, and negative social interactions can harm one's well-being (Rook, 2001).

To answer the fourth research question, data collected in the context of the “Informal Care” study by Statistics Netherlands and The Netherlands Institute for Social Research in 2007 were used. The data collection was carried out in two steps. In the first step, informal caregivers were identified using four screening questions included in the Labor Force Survey by Statistics Netherlands in 2007. A representative sample of Dutch adults (N = 54451) aged 18 years old and over
from different areas (i.e., rural, urban and mixed) were asked whether they had provided care in the last twelve months for a family member who was severely ill or needed assistance, for longer than two weeks because of an illness, accident or hospital admission, for someone who was chronically ill or impaired or for other reasons. Of the identified 4484 caregivers, 2813 participated in the follow-up written questionnaire on informal caregiving. To adjust for selective non-response, the remaining sample was weighted for a number of characteristics (i.e., gender, age, marital status or urbanization grade). Respondents provided information on various aspects of caregiving, the caregiver's burden, their own characteristics, and the characteristics of their care recipients and other available caregivers.

Outline of the Book

This dissertation contains four empirical studies answering four independent, general research questions. In Chapter 2, I examine the impact of siblings' caregiving and characteristics on an individual child's caregiving behavior. In Chapter 3, I look at issues of sharing the care and equality in caregiving intensity among siblings. In Chapter 4, I answer research question three and look at gender differences in parental support and their changes over time by taking into account egalitarian gender role ideology. Chapter 5 answers research question four by investigating whether the supportiveness of caregiving networks affects a child's caregiver burden. Chapter 6 summarizes the findings of the previous four chapters and discusses the main results and the theoretical, methodological and practical implications of the study.