Van je familie... : zorg, familie en sekse in de mantelzorg

Citation for published version (APA):

Potting, M. A. C. J. (2001). *Van je familie... : zorg, familie en sekse in de mantelzorg*. Aksant.

Document status and date:
Published: 01/01/2001

Document Version:
Publisher's PDF, also known as Version of record

Please check the document version of this publication:

Summary

Informal care or family care has been an important political and scientific topic for some years. The growing numbers of elderly people, the expected increase in care demands and the rising costs of formal health services – all these factors have contributed to a growing interest in the care provided by people themselves and to each other. In the past two decades, family care has become the subject of much scientific study. It has become a popular object of study in such fields as gerontology, sociology, social psychology and women's studies. This publication adds to the existing body of knowledge on informal care.

The research described in this thesis focuses on the help offered by sons and daughters to their elderly parents in the Netherlands. The research aims to contribute to theoretical discussions about family care and it centers around three important themes: care, family and gender. The central questions in this study are: *how* do people care for one another in the context of the family? And *how* is meaning assigned to the concepts of 'family' and 'care' within the caregiving process? The third research question focuses on gender issues: *which* role does gender play in family care? In answering these questions the starting point was to refrain from using the assumptions and presuppositions made in existing studies and policies on informal care, taking a critical attitude towards them instead. Qualitative research methods are more suited for answering questions like 'how' and 'why'. Intensive methods of research have been designed specifically to gain insight into processes and into the way people give meaning to their life and actions.

For this study, 26 persons (17 daughters and 9 sons) from 8 different families were interviewed in depth about the care they provided to their elderly parents. Several persons from each family were asked about the way they themselves and their family offered care. Different viewpoints on the organization of care for the parent within the family were collected in this way. All the families concerned (originally) lived in the southern parts of the Netherlands, and the respondents' average age was about 55 years.

In chapter three, a critical analysis is made of the so-called central caregiver model. In the fields of both research and policy it is often taken as a 'fact' that care is not evenly divided among family members. Usually a central caregiver is identified, who is supposed to give most of the care and bear most of the responsibility for it. Researchers not only tend to draw this conclusion, but also to base their research on it. In this chapter an alternative is given for the practice of 'identifying the central caregiver'.

First it is shown that there are many ways for families to spread caring responsibilities. While in some families there may be one particular caretaker who does a large part of the caring, this does not necessarily mean that other family members do not make a considerable contribution as well. In other families the care may be divided between sons and daughters without there being a central caregiver in the family. In these families caregiving is a collective responsibility, even though they may have assigned certain tasks to certain family members.

Secondly this chapter illustrates that caregiving in a family is a process that usually develops over several years, during which major changes can take place in the way the care is organized. Different persons may have different roles in the caregiving process throughout the years. A model such as 'the central caregiver' fails to account for these changes over time.

A third way of looking at the division of care within families that is illustrated in this chapter deals with the question of what sort of 'care' is provided. Traditionally, care is defined as performing Activities of Daily Life and Household Activities of Daily Life. Examples of tasks usually taken into account in research on this topic are: helping with personal care, cooking, doing the laundry and cleaning. Since this type of activities is usually carried out by women, most researchers conclude that women give more care than men. These groups of tasks are also strongly interconnected: if you do the one you are more likely to do the other too. In the study described in this book, care was not predefined. It was left to the respondents to indicate what kind of activities they considered to be part of the caregiving experience. As a result, a much broader range of tasks and activities were described as being important and vital aspects of caregiving. When this wide array of activities is taken into account, it turns out to be much more difficult to identify one person as being responsible for all these activities. Broadening the definition of care thus not only reveals a larger number of caregivers, but also highlights the contribution of men to the caregiving process.

The fourth way in which the central caregiver model was refined has to do with the multiple perspectives on one particular caregiving situation that were gathered in this study. Several persons from one family were asked about their views on how they themselves and the family as a whole offered care to the

parent concerned. It was obvious that each member of the family held his or her individual opinion on the way things were handled and on whether they were pleased or annoyed with this. Since all family members have their own caregiving experiences and attach personal meanings to them, there is no 'single' truth about the care given in a family. While one daughter may consider herself to be the most important caregiver, her brother or sister may disagree. Collecting data about family care from more than one family member is a way of refining the central caregiver model as such.

The fourth chapter of this book explores the meaning of the term 'family' in the context of family caregiving. Although most researchers acknowledge that the family is the main provider of informal care, they do not specify what 'family' is and means in their studies. In this publication the meaning of 'family' in family care is not taken for granted but rather an object of inquiry.

When asked to explain why the care given in their family has taken a certain pattern or how this pattern has come to exist, respondents tend to refer to their family history. Factors taken into consideration when thinking about current caregiving include the way things were done in the past, communication patterns that have formed over the years, and the way expectations about brothers and sisters have developed throughout family life. For respondents the history of their family and its members not only gives meaning to the caregiving, but also functions as an illustration of how things are done or meant to be done in their family.

Another important aspect of 'family' in the caregiving process is its perceived 'identity'. Respondents often describe their family as having a certain identity, for example 'we are a close-knit, caring family' or 'we are a quarrelsome family'. This shared family identity can offer respondents an explanation of why the care in their family is provided in a particular way and can make patterns of communicating about the care understandable and even logical and inevitable.

A special relationship exists between caregiving and family. Care is usually given because of the relationship between the caregiver and the care-receiver. Very often the motivation to care stems from the feelings of love and caring felt for the parent in need of care. But even when such positive emotions are lacking, the family bond is usually a motivation in itself to care for one's parents. Care and family are intrinsically intertwined: care is given because of the family ties. At the same time, the things done for a family member in need are often defined as care. When need and dependence become part of a relationship between family members, the character of all sorts of activities change. Playing a game of cards with one's mother is no longer just an expression of a shared

hobby, but may become part of the caregiving process as well. In this way respondents describe a range of activities as central elements of caregiving – activities which might be considered as being quite something else in other contexts but become an aspect of care in the context of family and dependency.

The family history, the family's identity and the special relationship between family and care are all very important aspects of the way 'family' is given meaning in the caregiving process. These different aspects not only make it clear to the respondents – and hence to the researcher – why the care in their family has taken a certain form and meaning, but also guide them through the process itself. Patterns and ideas from the past, the identified commonality between family members and the special meaning of family and care in the context of caregiving all present examples of how the care 'should' be dealt with in one's family. In this book the term family-script is introduced as a way of describing how the actions and expectations of family members are influenced by notions of 'family'. Just like the concept of script, as used in Science and Technology Studies, family-script entails not only the boundaries people encounter when giving shape and meaning to their actions, but also the freedom to find individual paths and maybe cross these boundaries. The fact that people are part of a family and the meaning they personally attach to this membership affect the way they individually and collectively give shape and meaning to the provision of care.

In the fifth chapter, a closer look is taken at the way family members negotiate the division of care. Special attention is devoted to the role played by gender in these negotiations. When trying to explain how task divisions have developed in a family, researchers traditionally look at variables such as gender, proximity, work status and genealogy. It is often assumed that there is a strong (statistical) relationship between these variables and the way care is divided. The number of hours spent in paid employment or the time necessary to reach a parent's home, for example, are considered important factors in determining who will take on certain responsibilities. Gender is considered to be the most important predicting variable: being a woman means to be caring.

In this study a slightly different position is taken. The central question is not concerned with the factors that determine who performs which tasks, but with how these 'factors' work. The respondents in this study frequently offer the same type of explanations as to why certain tasks and responsibilities are divided in a certain way: 'I provide so much care because I live near my parent', or 'Isn't it always the women who do most of the work?' When taking a closer look, however, the arguments appear less self-evident. Whether arguments are considered valid or not is not primarily related to their content (work, gender,

proximity) but to the value and meaning attached to them by other family members. Negotiations about care in a family do not hedge so much on the objective content of arguments but rather on the subjective meaning attached to these arguments. An essential consideration in assigning meaning to a particular argument is to what extent it is considered as an illustration of someone's willingness to participate in caregiving. For family members it is important that their siblings accept and acknowledge their reasons not to provide (so much) care. Arguments that refer to an inability rather than an unwillingness to offer care are more easily accepted as valid and legitimate. However, it is not always easy to make the distinction between unwillingness and inability.

Gender plays an important role in the process of negotiating family responsibilities and dividing care tasks. Arguments involve a gender-related quality. Certain arguments are used more often by women or gain validity more easily when used by women, while others are more the domain of men. In general men tend to present more arguments than women for failing to provide care, and these are more easily accepted. This explains in part why women are so often 'the designated carers' in a family. But this study also shows that the gender-related explanation for the division of caregiving is not as straightforward as is often assumed. Given the significant differences within and between families in the way arguments are given meaning and legitimacy and the way gender influences this negotiation process, it is obvious that there are no general rules. Gender is always an important issue in the negotiation process, but *how* important it is, *how* it influences this process and with *what* result cannot be safely predicted and is highly variant. It is the particular family context which accounts for the way gender is perceived.

The final chapter of this thesis summarizes the main results of this study and makes some recommendations for policy and research on family care. It deals with the relationship between research and policy in the field of family care. For many years there has been a strong link between scientific research into family care and family care policies. It is argued that the main body of research essentially plays a technical role in policymaking. Research on family care usually starts from the goals and objectives formulated by policymakers. It aims at answering major policy questions and tries to find solutions for problems defined by policymakers. The study described in this book started from a different position. Assumptions and presuppositions that are common in both policy and research were not taken for granted but were studied critically. Different types of research methods and theoretical perspectives were chosen to be able to take this critical stance. This resulted in a study which adds important nuances and alternative viewpoints to many commonly accepted ideas about family care. A

family discourse was introduced to talk and think about family care. It is the family, rather than individual caregiver, that should be studied as the provider of care. In offering a different way to look at, talk about and understand family care, this study can play more of a cultural than a technical role in policy-making. It emphasizes the differences occurring in the provision of family care and stresses its diversity in practice.