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## The frail elderly, family network and public home help services : a pilot study of the parties' perception of the help and their reciprocal relationships

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# The frail elderly, family network and public home help Services<sup>1</sup>

A pilot study of the parties' perception of the help and their reciprocal relationships

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## Abstract

Se inledning!

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## **Introduction**

The family with the elderly and the home help workers' team constitute two organisations, which meet in the care work. In this context the family is extended and often constitute not only members from the nuclear family but also other members of the network of relatives, whom take part in the care of the elderly. The extended family may in some cases include four generations (Finch & Mason, 1993).

Home-help for elderly people have expanded in Sweden during the period 1960 - 1980. This was due partly upon the prevailing ideology that it is important for frail elderly to stay in their own homes. Due to this expansion the local communities have developed their public home-care organisations. Different kinds of autonomous group organisation predominate (Olsson et al, 1995). Small work groups take responsibility for home help service in local areas. Home-helpers organise their job themselves, exchange experiences and give each other emotional support.

In Sweden both home care and institutional care of the elderly has decreased during the 1980<sup>th</sup> and 1990<sup>th</sup> in spite of the fact that the proportion elderly over 80 years (4,5 % of the total population) has increased 60 % since 1980. Twenty-two per cent of the women and 16 % of the men over 80 were cared for in their own home 1996. This development is said to have caused relatives to care for their frail elderly in the homes side by side by the home help services in an increasing degree (Johansson, 1991; Szebehely, 1998). Public care and service has an important impact on the interaction pattern between family members (Hendriksen, 1989; Johansson, 1999; Bass m fl, 1999). Home care may serve as an intervention that influences the health, well-being and life quality of the elderly and other family members. This intervention may have positive as well as negative effects. Problems and conflicts may arise in the interaction between the family members and between the family and the public help services (see McGoldrick & Gerson, 1989). We need more knowledge about these processes.

In a research project<sup>1</sup> the family and the home help services are studied as two organisations, which interact in the care of the elderly. We start with the hypothesis that the relation between the parties will have an impact on the character and quality of the care. We also think that the quality of the interaction will have an impact on the health and wellbeing of the elderly (see Olsson, 1991, 1998; Olsson & Ingvad, 1999).

## **Background**

### *The dynamics and functions of the family*

The family concept will have different character in different phases of the life of the members (McGoldrick & Gerson, 1989). Therefore the family can be best described from a life cycle perspective. This fact is emphasised in several gerontological works about social support of the elderly (e g Parrin & Stephens, 1990; Brubaker, 1990; Hansson & Carpenter, 1990; Bornat m fl, 1999). Care to the elderly is given by near as well as distant relatives. Noeck (1987) defines the family of the elderly as extended embracing children and siblings as well as more distant relatives having an important role in the life of the elderly. McGoldrick & Gerson (1989) emphasise that the responsibility of the care of the elderly may be "delegated" to certain family members in an early phase in the family life cycle of the elderly.

In their classic theory, Parsons and Bales (1955, 1956) claim that the family has a special role structure that makes a ground for the interaction pattern. This role structure is based on

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<sup>1</sup> The project is financially sponsored by The Swedish Foundation for Health Care Sciences and Allergy Research, the Vårdal foundation.

two types of tasks, the instrumental tasks and the expressive tasks. One important task for the family is to regulate the emotional life of the members. Family studies have shown that one special member may function as a scapegoat (Vogel & Bell, 1968) in order to regulate emotional strains. Such processes cannot be excluded in the interaction between the elderly, the caring relatives and the professional carers. In extreme cases this may be manifested in more or less severe abuse (Ingvad, 1999; Fear, 1999; Lowenstein, 1999; Saveman, 1999).

There often is a long history of mutual aid and emotional engagement between caregiving relatives and the elderly they care for (Wenger, 1987). Even if the care work may involve both physical and mental strain, the family members may experience satisfaction, self worth and dignity in giving care if the relation is rewarding (Wenger, 1987; Gordon & Easton, 1993; Furåker & Mossberg, 1997). Masciocchi *et al* (1984) points to several elements that may be important for the caregiving family members, e. g. their reaction to the dependence and weakness of the elderly and the character and quality of earlier social interaction in the family. A negotiation process starts in the family how to handle the often sudden increased need of care of the elderly. Earlier conflicts in the family may then reappear. Parsons *et al* (1989) has shown that the elderly may reduce the communication to relatives in order to avoid conflicts and to reduce the burden of the family.

#### *The character of the care relationship*

In a longitudinal project we have studied the home help services in three typical Swedish municipalities since 1993 (Olsson & Ingvad, 1992; Olsson *et al*, 1994a; Olsson & Ingvad, 1996; Olsson & Ingvad 2000). Questionnaires, qualitative interviews and longitudinal case studies have been used to investigate the teams of the home help workers and the relation between the home help worker, the recipient and family members. The results show that the elderly, the family members, the home help workers and other actors in the home care organisation exercise a strong emotional influence on each other. Earlier research discuss the emotional interaction in care work in terms of emotional support from the caregiver and mental strain (e g Thulin, 1987; Eliasson & Thulin, 1989; Simonen, 1990; Ungerson, 1990; James, 1992). We want to emphasise that the emotional interaction is a dynamic process between the parties that may influence the content and the quality of the care (Ingvad & Olsson, 1999, Ingvad 2000).

We use the climate concept to describe the emotional aspects of the care relationship and we have isolated four meaningful dimensions of what we call *the caring climate*: uncertainty –conflict, closeness, flow of communication and control (Olsson & Ingvad, 1999; 2001). Results show that home care workers are more likely than the recipients to experience a higher degree of emotionality in the relationship. This may be an expression of a wish for a warm and close relationship and a desire to be kind and loving or loved and appreciated (see also Kaye, 1986). There is symmetry between the parties in the perception of a negative climate. However if one party perceives the climate as close the other party is more likely to perceive it as rational or instrumental. The organisational processes, especially the group climate of the work team, principally influence the home care recipients' perceptions. Age and gender of the recipients and the workers' own age principally influence the workers' perceptions.

Our studies (Ingvad & Olsson, 1999a, 1999b) show that in the majority of the cases, the home care worker and the home care recipient seem to cope with the mutual expectations for the practical, social and emotional exchange, through silent adaptation. The home care worker may handle the problems surrounding the exchange by “tuning in” to the care recipient and trying out different roles. If there is an open conflict, the home care worker often is coping by using avoidance or the exercise of power. The home care worker who experiences the emotional exchange as dissatisfying tends to attribute “troublesome” to the home care

recipient. They then tend to underrate the situational factors and overrate the significance of characteristics in the home care recipient or their relatives. Social constructions such as assuming a mothering role or idealising the client can provide the home care worker with a positive emotional exchange in the relationship with the recipient that otherwise had been difficult. The dependence on help can also mean that the recipient adopts a role of gratefulness in fear of otherwise losing the home care worker's emotional care. Showing warm feelings to the home care worker may be a way by which the recipients try to ensure that the affection they receive is real (Qureshi, 1990).

*The encounter between the elderly, family members and professional care-givers*

Several authors (Noelker & Bass, 1989, 1994; Olby, 1989; Litwak, 1985) have discussed different types of relationships developing between family members and the public services in the care of the elderly. Generally we can distinguish three forms of relationships:

1. *substituting*, when one party replace the other, e. g. when the home care worker becomes a substitute for a life partner
2. *complementing* when the parties give different kinds of help and together fulfils the total need of help
3. *supplementing* when one party gives help that is not possible for the other to fulfil

Several factors may influence what kind of relationship will develop, such as the law, the gender of the parties, the health of the elderly, the character of the family relationships and the views and motivation of the parties. According to the social law in Sweden you have right to receive aid from public home care services *if there is no other way to receive this help*. This condition means a potential risk for conflicts between the family and the public services if the distribution of responsibility is obscure. If the need of care of the elderly suddenly is heavily increased there will often be a crisis in the family. In this situation the family will "re-organise" to face the new care needs. The public services may have an important role to support in this process in the family. Conflicts may arise between family and care workers.

Our preliminary results show that the family members are more critical to the home care service than the elderly. The home help organisation often has difficulties to handle decision processes where family members are involved in the care. In a case study Ingvad (1999) noted how prejudices and a groupthink process (Janis, 1971) developed both in the family and the home help worker's team. The solution of the care situation for the elderly became deficient and a negative climate developed both in the family and in the worker's team. There was obscurity about how to divide the help work between the family and the home help workers and between the family members themselves. These results open a series of important questions, e.g. how family dynamics and organisational dynamics may influence the relationships between family members, the elderly and the home help workers. Our earlier studies have shown that the climate of the home help workers' team (Olsson m fl, 1995, 1999, 2000) is related to the recipients' judgement of the caring climate. The results also showed that the more workers who are involved in the care situation the more negative are the recipient's judgement of the caring climate.

### **Purpose**

In this study we explore how the family with the old person and the public home help services contribute to the care of the frail elderly and how they interact. We explore the character of the relationships between the old person, family members and the home help workers. We also focus on the significance of extended family networks, the health and quality of life of the elderly on experiences of the received help. *In this conference paper we report on a pilot*

*study with a limited number of cases.* Later we will present studies with more cases from different kinds of municipalities and make more extensive qualitative interviews with all three parties (the elderly, family members and home help workers). In this study we have not had opportunity to investigate the experiences of the workers.

### **Participants**

From a home help district in a large town with 122 recipients, 12 recipients has been interviewed. A questionnaire about the quality of the home care was sent to all recipients. All persons 80 year or more with care more than twice a week who had completed the questionnaire were chosen for interview. This was done a year after the questionnaire was sent to the recipients. During this year many persons had got worse health and did no longer stay in their own homes. Some had died. 42 persons fulfilled the criteria. A letter was sent to these recipients. They were asked to take part in an interview about the home help and care from relatives. A week later they were phoned to make arrangement for the interview in their homes.

Only 12 recipients could be interviewed. Eight said they were too sick, 6 returned mail, 1 person had no longer home care, 4 did not want to take part in the interview and 11 persons could not for unknown reasons be contacted on telephone. For ethical reason we have not tried to get more information about those we could not reach.

During the interview we asked the recipients to give name and address to the family members taking part in the home care. We got ten names. Nine of these completed the questionnaire mailed to them.

### **Methods**

1. *Characteristics of the home help* were registered through the questionnaire and the interview to the recipients:
  - a. *Frequency*, i. e. how often the care recipient receives help from a worker. This can vary from once a week to several times a day.
  - b. *Duration*, i. e. how long time the recipient has had home help services. This can vary from one month to several years.
  - c. *Continuity*, i. e. the number of home care workers assisting the care recipient. High continuity means that only one worker assists the care recipient. We also ask if the recipient has been acquainted with any of the helpers.
  - d. *Kind of help*, i. e. the content of the help in three categories: household (cleaning, foodpreparing etc); personal help (hygiene, dressing, walking etc); personal support (someone to talk with).
  
2. *The quality of the help* from the home help services and from family members is studied with a question of the overall quality in the interview with the recipient:  
What is your opinion on the help that you receive?  
Answer categories: Very satisfying (4); satisfying (3); unsatisfying (2); very unsatisfying (1).  
The relatives also have to judge the overall quality of their help to the recipient and their perception of the quality of the help from the home help services to the recipient with the same question.
  
3. *The emotional climate in the relationship with another party:*

The emotional climate in the relationship between the recipients, family members and the care workers is studied with the help of an adjective list (Olsson & Ingvad, 1999; 2000, 2001) consisting of 85 different adjectives representing common descriptions of atmosphere and feelings in relationships and groups (warm, uneasy, cold, calm, etc). The respondent is asked to choose those 15 adjectives that best describe her/his perception of the climate of the caregiving relationship.

In former studies (Olsson & Ingvad, 1999, 2000) we have explored the dimensions of the perception of the *emotional climate* of the relationship between home care recipient and home care worker by the help of the adjective list given to both parties. The responses on the adjective list were analysed with factor analysis and dimensions of climate perception were constructed. For the recipients two analysis were performed with 188 respectively 502 cases. On the basis of the two analyses and semantic analysis of similarities between the words, four climate dimensions have been constructed: *Uncertainty, Closeness, Flow of communication* and *Control* (see Table 1).

The measure of the caring climate is calculated on each dimension as the number of words chosen divided with the number of words in the dimension. An adjustment for the total number of words chosen by the respondent on the adjective list is made. Reliability is satisfactory for both recipients and for home care workers. In a validity analysis the measures were found to have meaningful relationships with different measures of quality of the home care work (Olsson & Ingvad, 2000). On the basis of the scoring on the caring climate dimensions, different types of caring climate were identified by help of cluster analysis (see Table 2).

Table 1. Adjectives in the dimensions of the perception of the caring climate as assessed by the home care recipients.

<b>Uncertainty</b>	<b>Closeness</b>	<b>Flow of communication</b>	<b>Control</b>
Uneasy	Loving	Open	Adult
Confused	Warm	Caring	Independent
Irritated	Harmonious	Easy-going	Safe
Uncertain	Happy	Active	Mature
Nervous	Humble	Calm	Orderly
Indifferent	Eulogistic	Personal	Important
Harassed	Pleasant	Light	Sensible
Disharmonious	Secure	Tolerant	Meaningful
Impersonal		Loyal	Stable
		Natural	
		Spontaneous	

In this study, the same dimensions are used for the relationships between the relative and the recipient, the recipient and the home care workers and between the relative and the home care workers. The measures are standardised according to a material consisting of 600 recipients judging their relationships to their home care workers (Olsson & Ingvad, 2000).

Table 2 Types of caring climate constructed on the bases of the dimensions of the perception of the climate of the home care relationship.

Party of the care relationship	Types of caring climate
Home care recipient	a. <i>Friendly</i> (high Flow of communication, low Uncertainty, low Control, medium Closeness) b. <i>Uncertain</i> (extremely high Uncertainty, extremely low on all other dimensions) c. <i>Emotional</i> (extremely high Closeness, low on all other dimensions) d. <i>Rational</i> (high Control, low on all other dimensions) e. <i>Quiet</i> (low values on all dimensions)

4. *The health and the quality of life of the elderly is measured by the following questions in the interview:*
  1. *How will you judge your general state of health?* There are five answer categories: 1. Very bad; 2. Rather bad; 3. Neither good nor bad; 4. Rather good; 5. Very good. The answer is coded as an overall measure on health.
  2. *What is important and meaningful in your everyday life?* This is an open question.
  3. *How do you think your life on the whole is now?* The answer categories are the same as for question 1. The answer is coded as a measure of quality of life.
  4. *Does it happen that you feel alone?* There are four answer categories: No, never (0); Seldom (1); Sometimes (2); Yes, often (3)
  5. *What can you manage on your own?* The elderly has to judge if she /he can manage 10 different functions: get up from bed; wash her/himself; bath and have a shower; go to the toilet; dress and undress; make food; eat without help; read; do the cleaning; go for a walk? The number of functions the elderly can manage is coded as a measure of *functional level*.

### **Data collection**

The recipients first completed a mailed questionnaire and were then interviewed in their homes. The relatives completed a mailed questionnaire. The questionnaires and the interview encompassed the following variables:

1. *The questionnaire to the recipients:* Age and gender; the character and frequency of the help; continuity of the care; quality of the care; the climate of the relationship to the home help worker.
2. *The interview with the recipients:* Back ground data; description of the relationship to home help workers; quality of the care; health, quality of life and meaning of everyday life; family network and perception of the relationships to relatives; character, frequency and quality of help from relatives; perception of relation between relatives and home care workers
3. *The questionnaire to the relatives:* Back ground data; contacts with the recipient; character and frequency of the care of the recipient; quality of the care; perception of the climate in the relationship to the recipient; perception of the quality of the care from the home help services; perception of the climate in the relationships to the home care workers.

### **Result**

In *Appendix 1* the results from all 12 cases are presented in graphic form. A template for the presentation of data is given in figure 1. Each case presentation comprises an overall picture of how the parties perceive the relationships to each other and between the others and how the

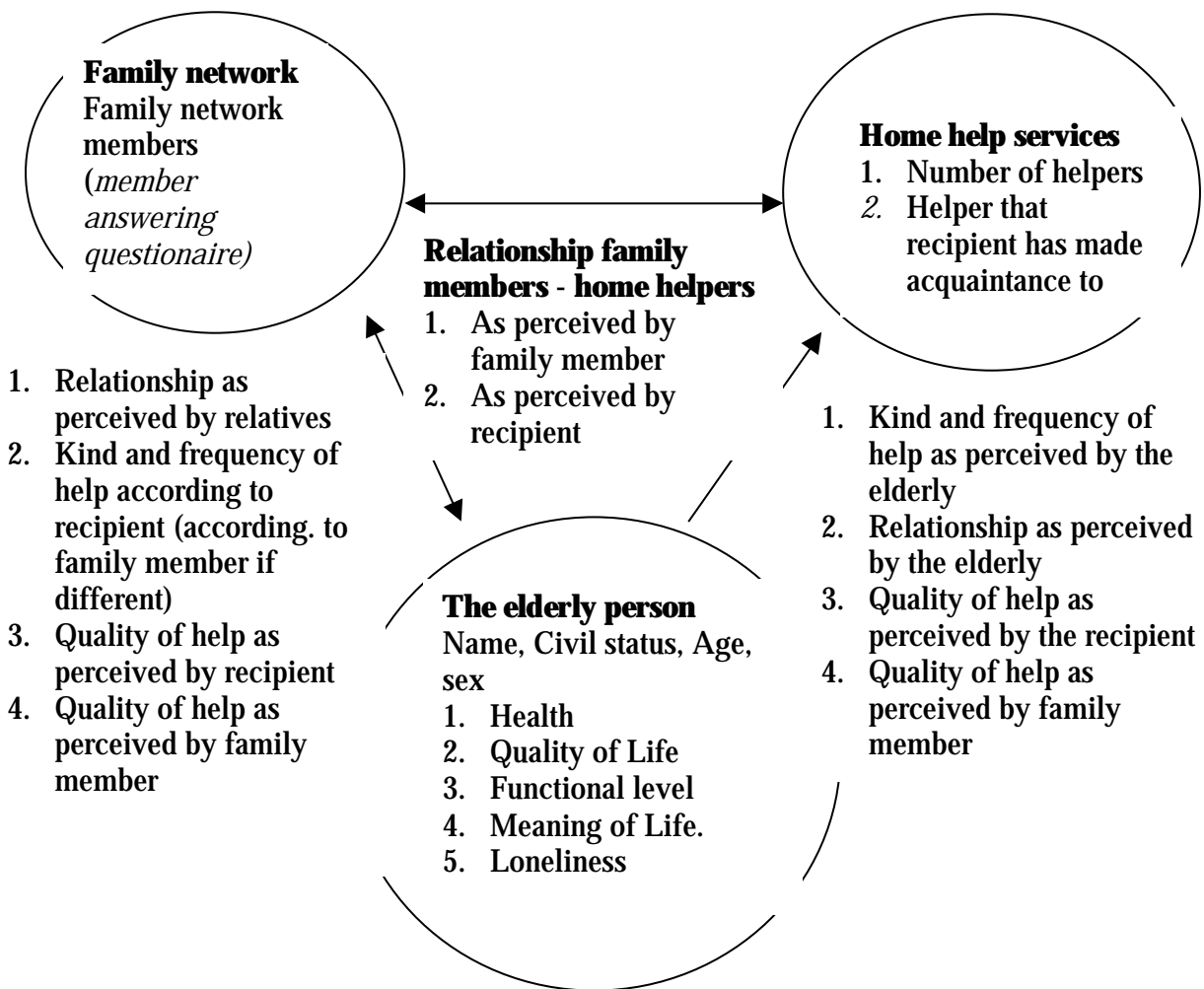


elderly perceive health and quality of life. The presentation also gives a picture of the family network of the elderly and what kind of help she/he receives from the different parties.

It is not possible to determine if the selection of cases is representative for people 80 or more, receiving help in their homes. Some of the selected persons said they were too sick to participate in the interview. Thus we may expect that the health of our cases are better than the overall group of home help recipients 80 or more. Perhaps the need of help is somewhat less in our sample than for the category as a whole. The distribution (in numbers) of the emotional climate of the elderly in the relationship to the home helper is as follow for our population (the number of persons interviewed within brackets): *Uncertain*: 8 (1); *Emotional*: 7 (2); *Rational*: 6 (1); *Friendly*: 12 (3); *Quiet*: 4 (2); *Friendly and rational*: 3 (2); *Uncertain and friendly*: 1 (1); *Uncertain and emotional*: 1 (0). This indicates there are perhaps too few with an uncertain relationship but overall the cases represents the total population very well in this respect.

In spite of the weaknesses in the smaller sample we think that the cases in the study can illuminate the help situation and the relationships between the parties and produce problem formulations for further investigation.

Figure 1 Template for data presentation of the cases



All cases have a lot of help from the public services. Almost all of them have help every day with household, personal help and some also mention that the home-helper gives personal support. In relation to this the relatives give rather limited help. For the majority of the cases they give help once a week or less. Also, there are differences in the kind of help given. Home helpers give basic help with daily living and the relatives give help with transport to extended activities outdoors, economic matters (bank), cloth shopping and sometimes help with household. In a majority of the cases the most important persons to the recipient for the tasks of daily living are the home-helpers. In most cases the parties give complementing help to the recipient. In *Case 5 and 11*, however, the relatives give the same type and frequency of help as the home-helper.

The help from the relatives may be very important for other reasons than the help from the home-helper. In some cases the recipient and the relatives define the help given from relatives in different terms. In *case 3* the recipient says that she receives help with household and transport while the relative answers that they don't give help at all. The opposite can be observed in *case 2* where the recipient says that the help from relatives is "not really help". In *case 7* the daughter answers that she gives help every week. The recipient, a man, talks about help once a month. What should be defined as help with daily living from the relatives seem to be obscure. The social contact may be more important than the help for both parties. Perhaps it is important for some recipients not to have a dependent role to the relatives but to have a more genuine family member role. It may also be important to the relative to be perceived as a family member rather than just as a helper (cf. Socialstyrelsen, 1994)

The relationship between relative and home-helper gives for most cases an impression of distance. In *case 2 and 7* the relatives experience an uncertain emotional climate and in *case 3* a rational climate. Almost all the relatives say that they have limited influence on the planning and performance of help from the home-helper (This result is not presented in the graphic figures in Appendix). There is, however, also one case (11) where the daughter gives as much help as the home-helper. The relationship in this case is experienced as co-operation. Recipients and relatives in many cases judge the home help different. In five cases (of eight cases with information from relatives) the relative give a somewhat lower value than the recipients do. In *case 2 and case 6* the family members judge the home help as unsatisfying, which are the only negative evaluations of quality in the material. This difference may be seen as a sign of marking a distance to the public helping system. The relative is outside this system but the recipient is inside it. Recipients in four cases (*6, 9, 10, 12*) say that there is no contact between these two parties. Perhaps they want to keep the two systems apart since they do not want to be involved in conflicts between them (cf. Ingvad, 1999).

It is possible that the recipients want to decide about the help together with the home-helper on their own. The relatives, on the other hand, try not to take over, which may contribute to the distance in the relationship between relatives and the home-helper. We have no information from the home-helpers in this study. We know however from an earlier study (Ingvad, 1999) that the two systems, the family and the home help organisation, may construct each other as negative and controlling parties. This seems to be the case when relatives want to take part in the decision process concerning the home help.

Compared to other studies (e g McCarmish-Svensson et al, 1999) the subjective health and quality of life in our sample of recipients is about the same or somewhat better than in a normal population of people 80 year old (with reservation for different methods). More than half of the recipients in our sample has indicated very good or rather good for both measurements of health and quality of life. Only two people have judged their health or life quality as bad or very bad. This is somewhat astonishing as people in our sample receive rather much public help. However, in one study Ingvad et al (1990) have shown that people

with much help and living at old peoples homes also have just as high ratings in subjective health as our sample.

The question about what is important in life gives about the same answer from most of the recipients. Contact with relatives, friends coming to visit and pals seem to be the most important content in life. The answers "to come outdoors" and similar replies, also indicate an interest in social contacts. The memory of a dead husband or wife may also be an important life content as in *Case 1*, who seems to live for the memory of the deceased husband. *Case 10*, with few relatives and a negative relationship to them says she has very bad health and rather bad quality of life. She cannot formulate any important life content. The recipients on the whole mention few other interests than social contacts. Many of them (also *case 10*) often look upon one of the home-helpers as a friend, which gives personal support (somebody to talk with). The frequent visit of the home-helper give a social contact, which may be a very important event in the everyday life of the recipient. Some of them remark that the home-helper is too much in a hurry, and they may thereby indicate that they miss the important social contact.

### Discussion

The main focus of this paper is the relationship between the family network and the public home help system in relation to the help need of the elderly. The results show that in most cases there is a clear difference between the help given from the family network and from the public home help services. The relation may be described as *complementary*. Only in one case, where the recipient has no contact with relatives, the home-helpers seem to have the whole responsibility (*substituting relationship*). The family members give help with low frequency and often limited to shopping, transport and other practical things that are not clearly within the definition of the help that can be given from public home help services. The later system gives the majority of the help needed for everyday living with a high frequency. The most important role of the family network is the social and emotional contact that also is the most important content of the life for many cases. The home-helper is also important as a friend. This means that both systems are important parts of the social world of the frail elderly.

. The results clearly illustrate that there are two different social systems with limited contact with each other. The formal help seems to be defined in such a way that it does not include aspects that are important tasks in the family sphere in the modern western society such as extended outdoor activity, cloth shopping, furnishing, bank and post. It is not obviously natural that the family members should help with more intimate household and personal tasks such as hygiene, dressing, cleaning and cooking. The family and formal public help services divide the responsibility in such a way that the home-helpers get the main responsibility for daily living of the elderly. It is possible that it is important for both organisations to emphasise their boundaries. The help from the family members is within their interest area e. g. economic matters and to maintain the emotional relationship and thereby keep the social organisation together.

The two systems seem to be relatively closed in relation to each other with limited degree of communication. The systems are dependent on each other and tensions can be observed between them. The family members feel that they have no influence on the home help situation and from earlier studies we know that the home-helpers may feel criticised by relatives (cf. Bergh, 1996). The family members in this study value the home help somewhat lower than the recipients do. The elderly themselves are not very interested in the contact between the systems. They often say there is no contact. For them both systems are very important and perhaps the home-helper becomes a friend that contributes to quality of life. Perhaps the elderly want to keep the two systems apart in order to preserve the benefits of

both systems. Conflict between the systems could be very destructive for their life situation. On the other hand, we mean that more practical co-operation and discussion about the help situation would be needed to construct an optimal assistance for the daily living of the elderly. It is important that people in both systems are aware of what gives life quality for the elderly.

As social contact is the most important life content in most of our cases, we can assume that public help services most probably is very important for the health and quality of life of the recipients. The frequent visit of the home-helper contributes to the social content of the everyday life of the elderly, like that of a friend. However home help services in Sweden has during the 1990's aimed at getting more efficiency in the work. Home-helpers have less time to sit down and have a chat or to take a walk together with the elderly. This may be a very serious quality problem in the home help services for many of the recipients, as the family members seem not to visit them very often.

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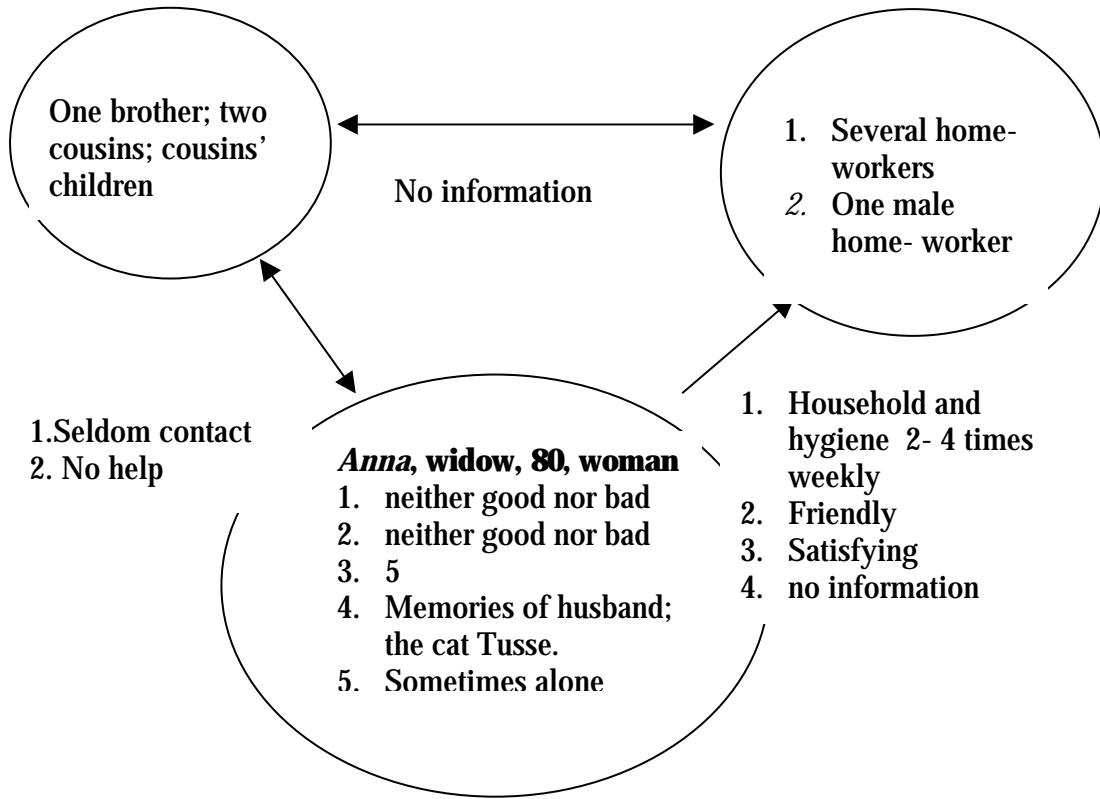
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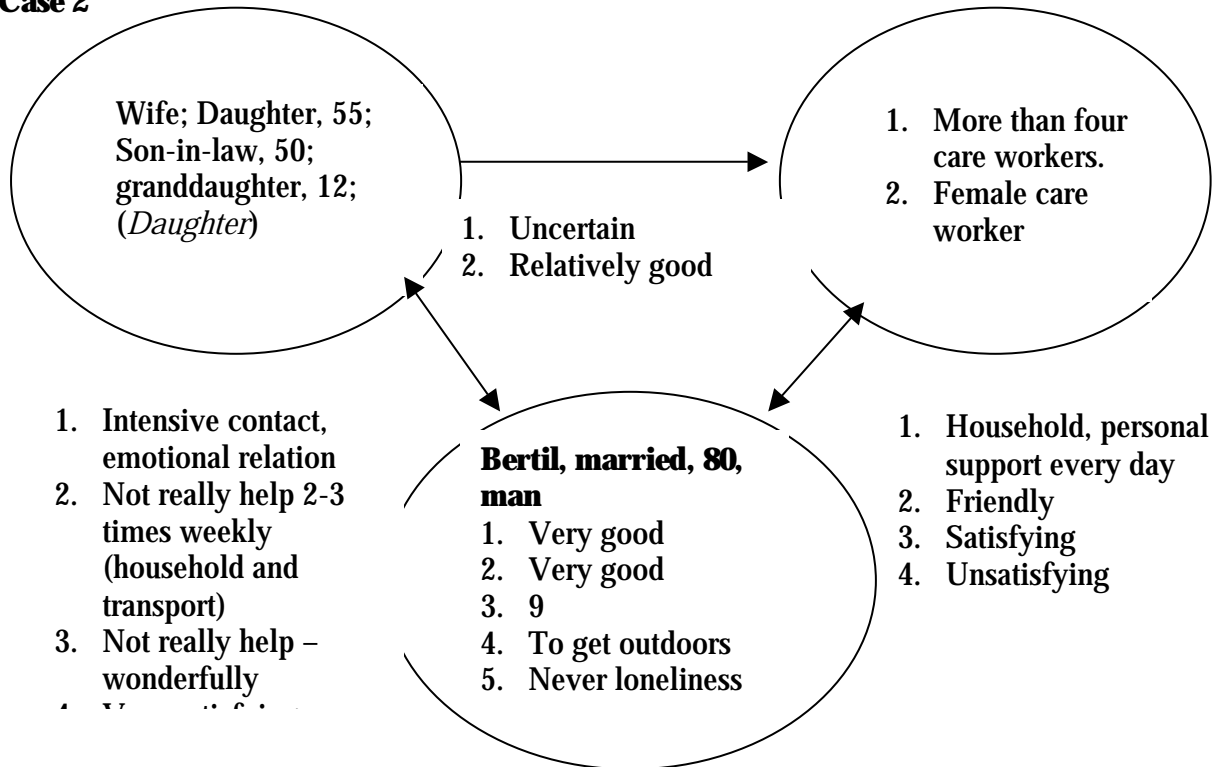
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**Presentation of results for all cases**

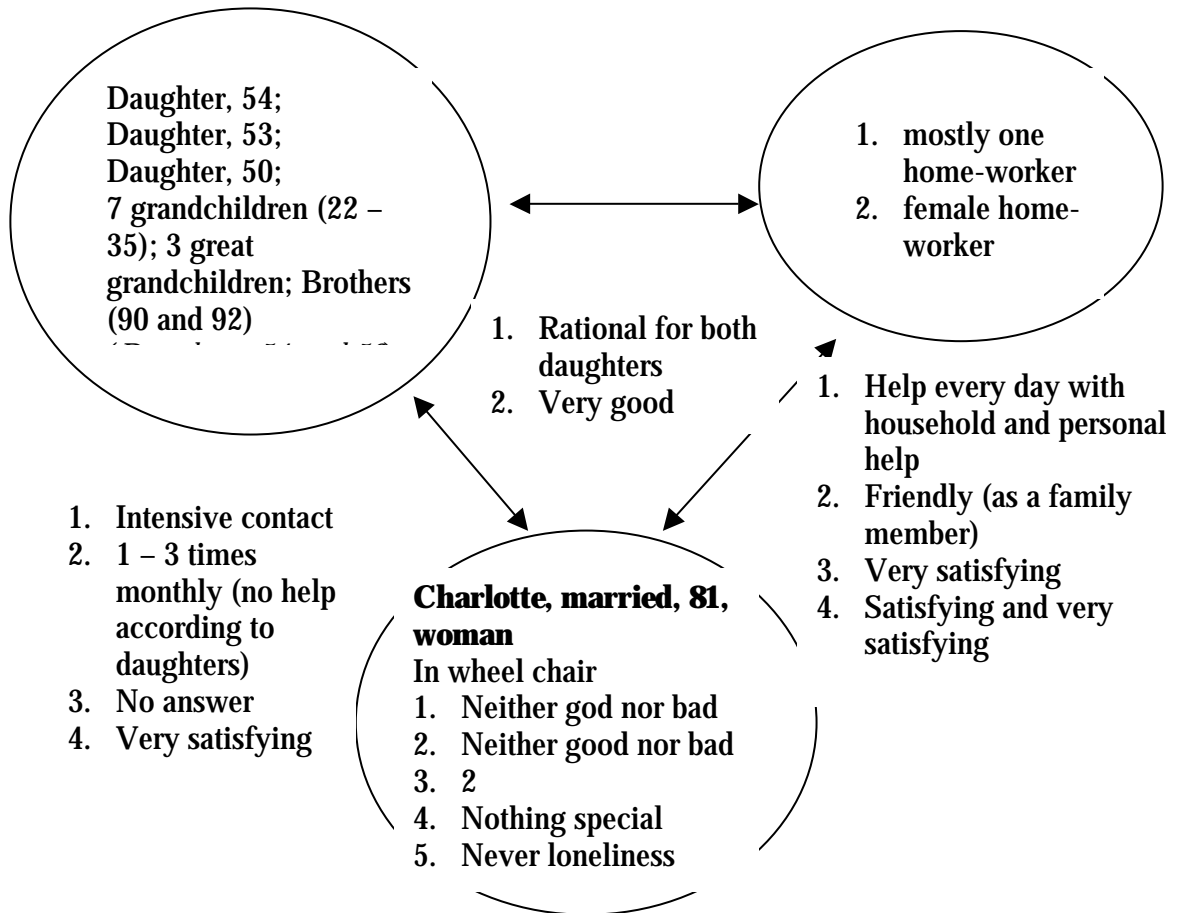
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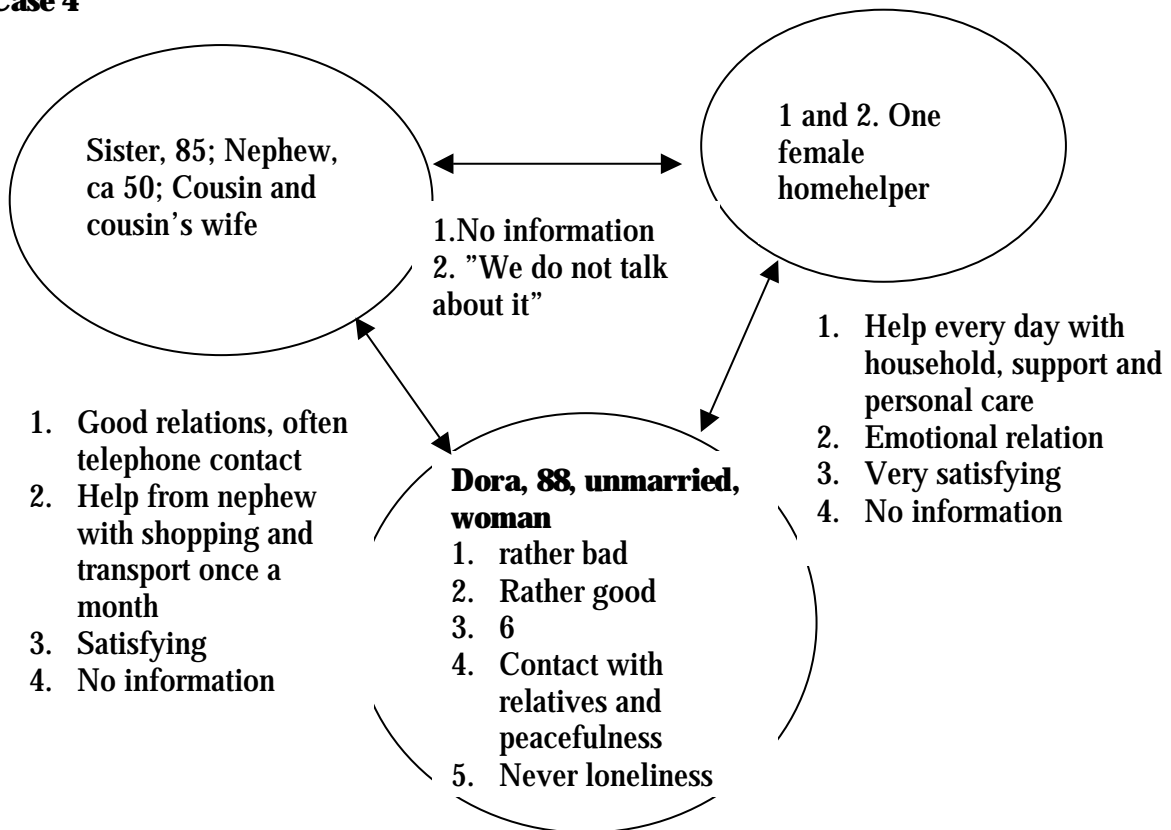
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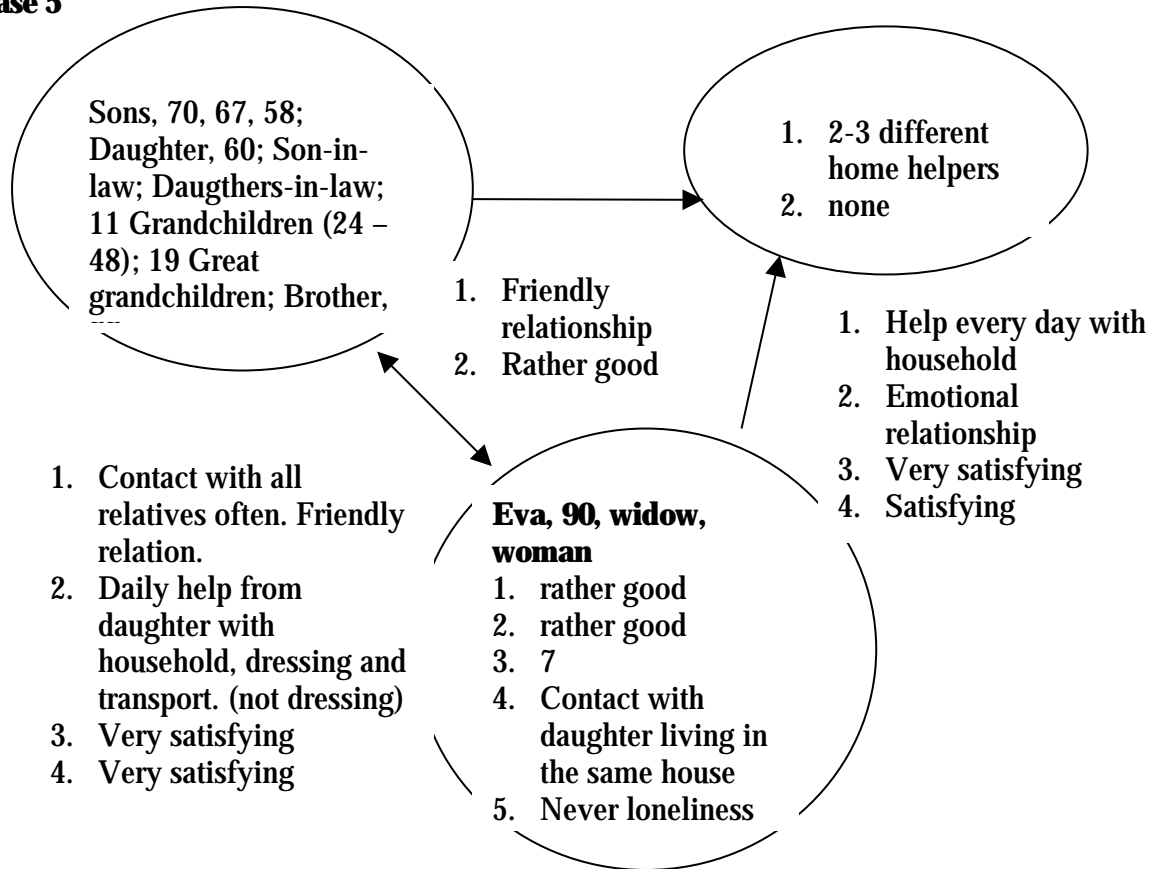


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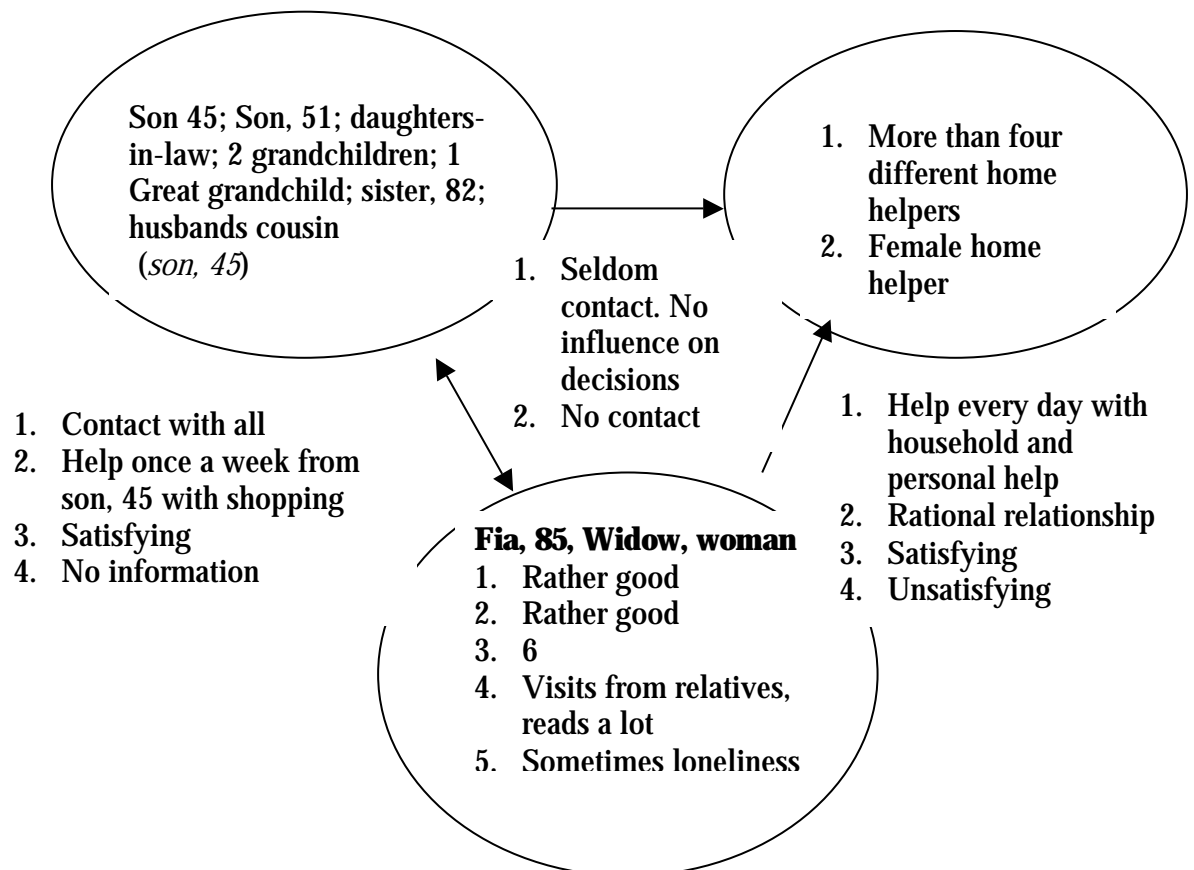




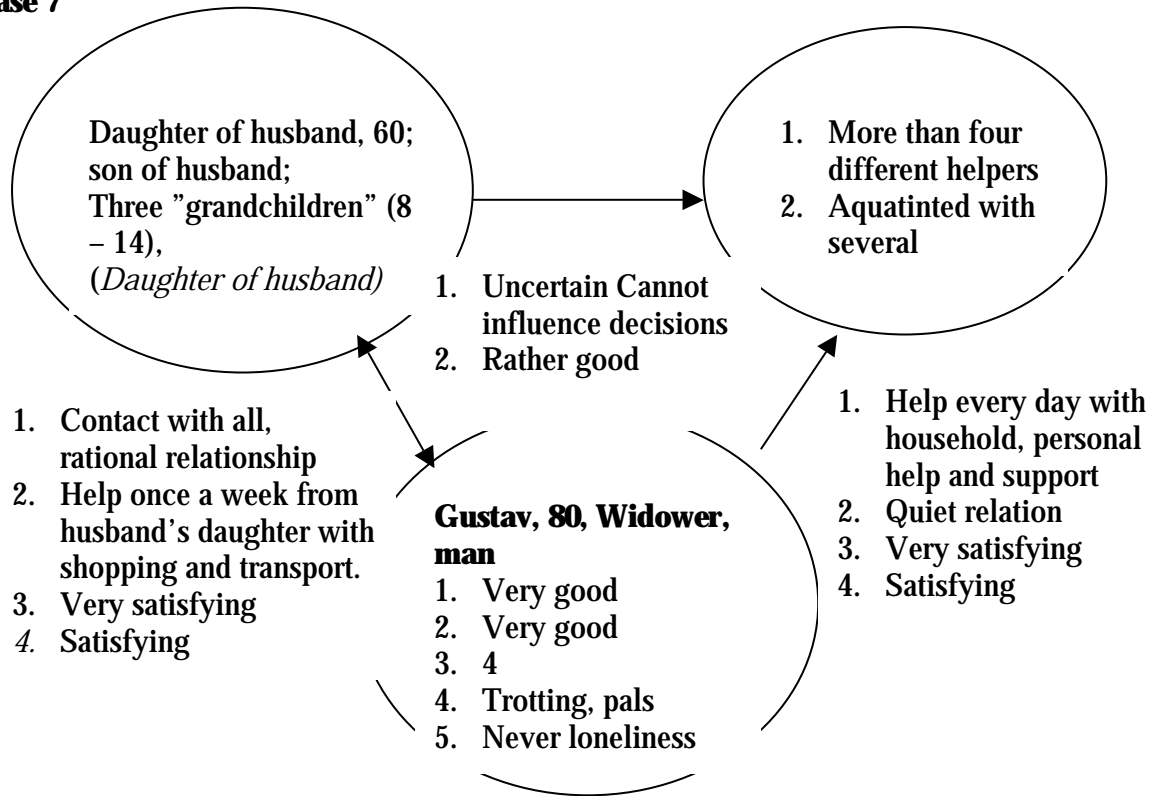
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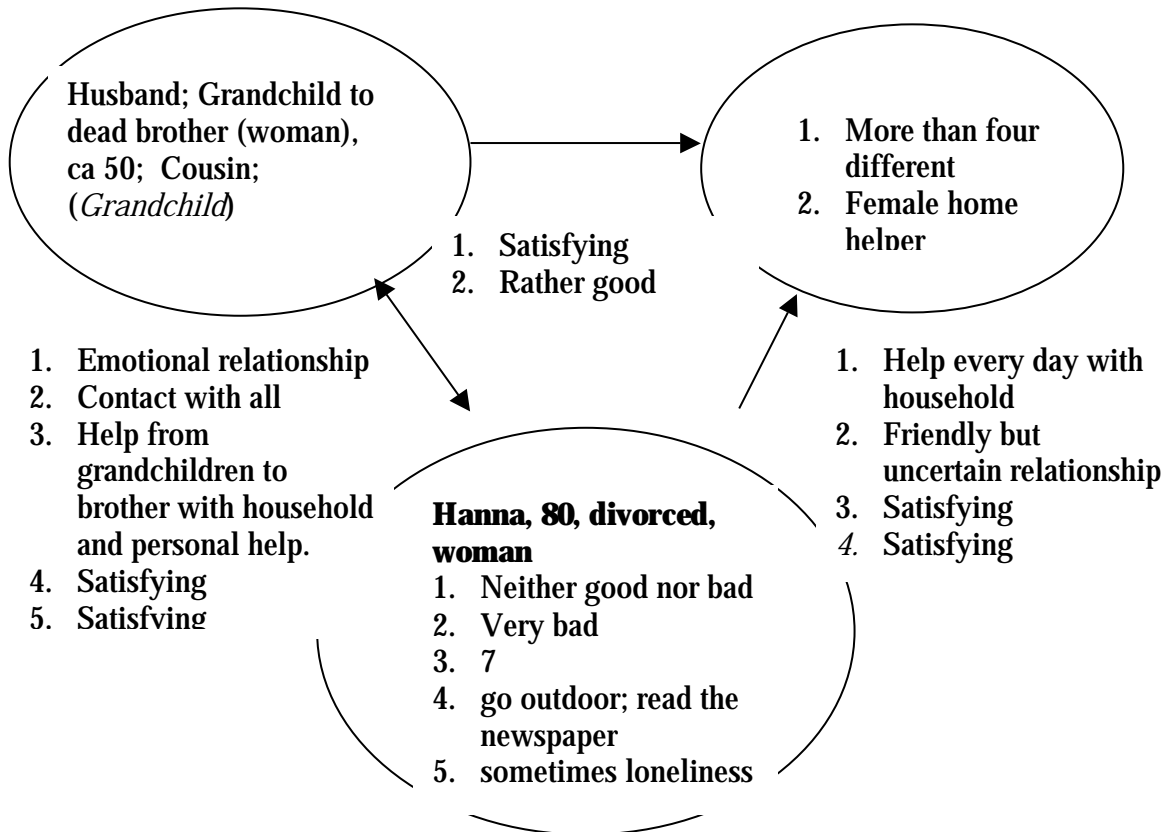
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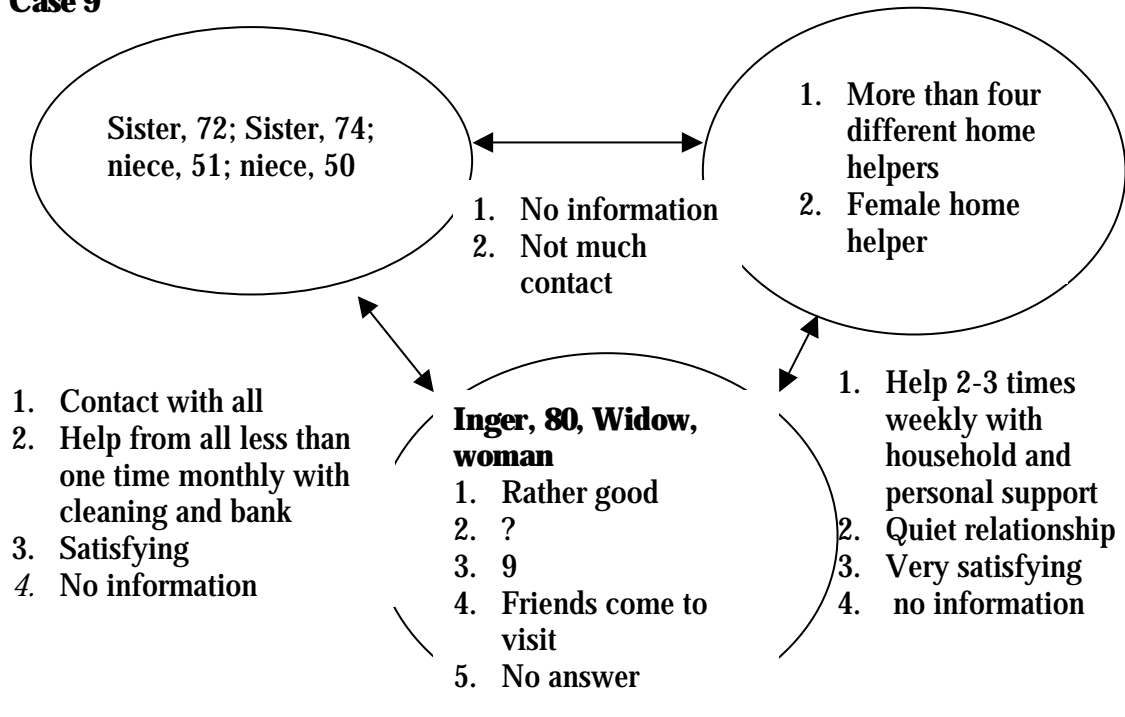
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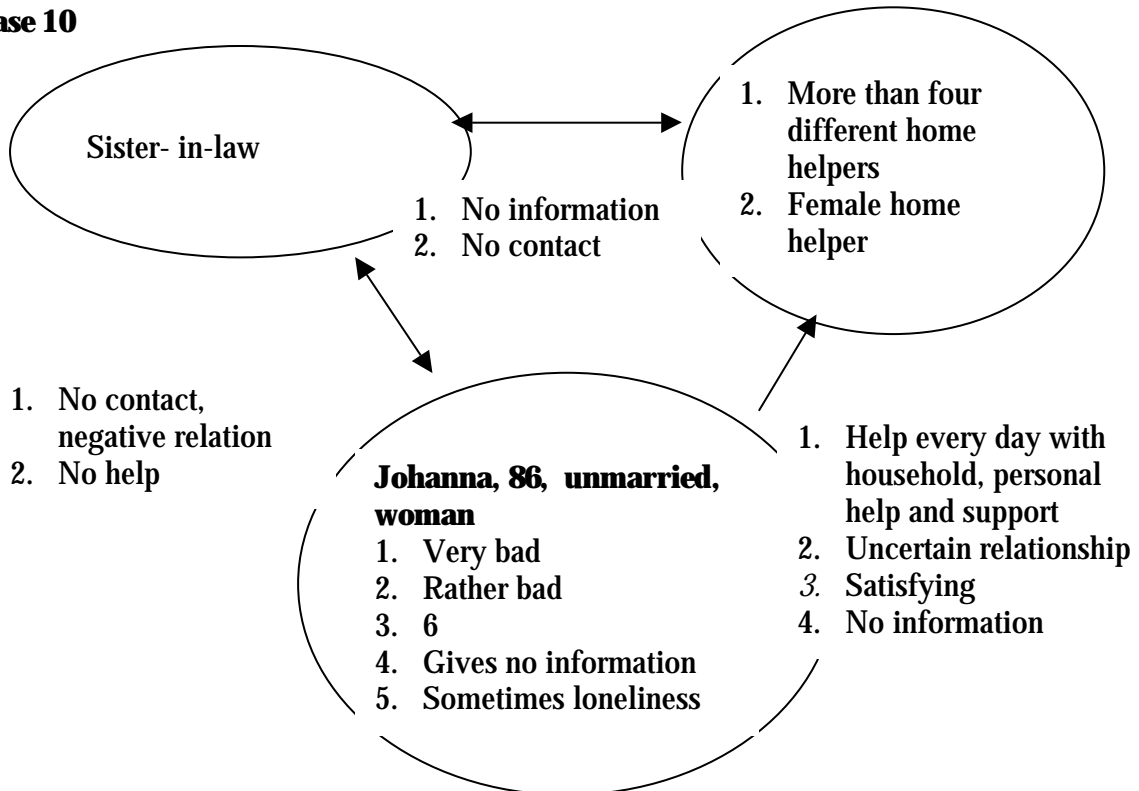
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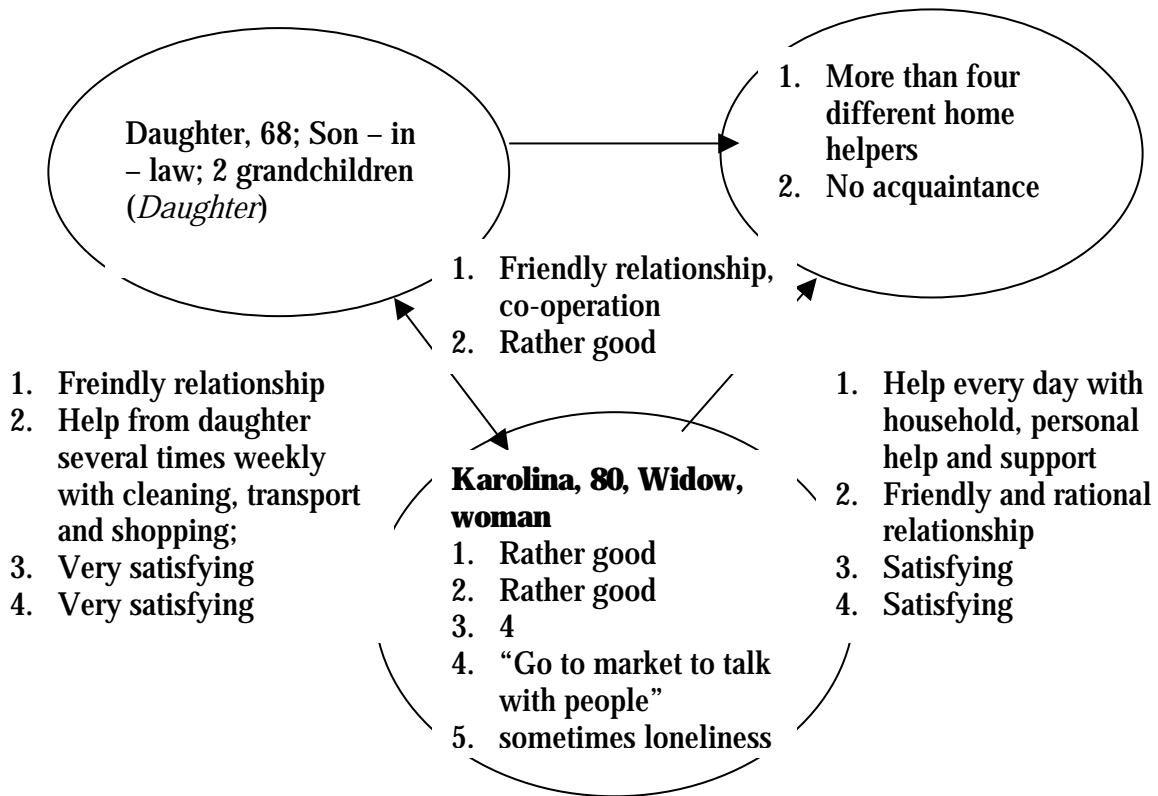
**Case 9**



**Case 10**



**Case 11**



**Case 12**

