

## TAKING CARE OF THE ELDERLY MOTHER IN HOMECARE CONTEXT: DAUGHTERS PERSPECTIVE<sup>1</sup>

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**ABSTRACT:** Qualitative study based on the Social Phenomenology of Alfred Schütz with the aim of understanding the care for the dependent elderly mother from the daughter's point of view. Achieved in 2011 with ten participants, who were interviewed at home from their mothers. The typical caring daughter's action makes her as being the one who establishes a caring relation focused by preoccupation with the situation of the elderly mother's dependency, which generates one inversion of roles from mother and daughter. It shows a physical, psychic and emotional wearing resulting from the day by day caring, needing a social support to help her in this care. Looking forward to keeping the mother's life and postponing as much as possible the end of her life. This result arising to the care professionals concerning planning and achieving the home care to think in effective articulation between the requirements both daughter and elderly mothers show.

**DESCRIPTORS:** Nursing. Aging. Family relations. Caregivers. Qualitative research.

## CUIDAR DA MÃE IDOSA NO CONTEXTO DOMICILIAR: PERSPECTIVA DE FILHAS

**RESUMO:** Estudo qualitativo fundamentado na Fenomenologia Social de Alfred Schütz, com o objetivo de compreender o cuidado à mãe idosa dependente, na perspectiva de filhas. Realizado em 2011, com dez participantes, as quais foram entrevistadas no domicílio de suas mães. As características típicas da ação das filhas cuidadoras constituem-nas como sendo aquelas que estabelecem uma relação de cuidado marcada pela preocupação com a situação de dependência da mãe idosa, o que gera uma inversão de papéis de mãe e filha. Apresentam um desgaste físico, psíquico e emocional decorrente do cuidar cotidiano, necessitando de uma rede de suporte social para auxiliá-las nesse cuidado. Busca preservar a vida de sua mãe e postergar o quanto possível seu término. Este resultado suscita que os profissionais de saúde ao planejarem e realizarem o cuidado domiciliar, pensem em uma articulação efetiva entre as demandas que filhas e mães idosas apresentam.

**DESCRIPTORES:** Enfermagem. Envelhecimento. Relações familiares. Cuidadores. Pesquisa qualitativa.

## CUIDAR DE UNA MADRE ANCIANA EN EL CONTEXTO DOMICILIAR: PERSPECTIVA DE LAS HIJAS

**RESUMEN:** Estudio cualitativo fundamentado en la fenomenología Social de Alfred Schütz con objetivo de comprender el cuidado de una madre anciana dependiente desde la perspectiva de hijas. Realizado en 2011, con diez participantes, que fueron entrevistadas en los domicilios de sus madres. La acción típica de las hijas cuidadoras es la que establecen una relación de cuidado marcada por la preocupación con la situación de dependencia de su madre anciana, con inversión de papeles de madre e hija. Presentan un desgaste físico, psíquico y emocional decurrente del cuidado cotidiano, necesitando una red de apoyo social para ayudarla. Busca preservar la vida de su madre y postergar, cuanto sea posible, el término de la misma. Los profesionales de salud, al planificar y realizar el cuidado domiciliar, deben pensar en una articulación efectiva entre las demandas que hijas y madres ancianas presentan.

**DESCRIPTORES:** Enfermería. Envejecimiento. Relaciones familiares. Cuidadores. Investigación cualitativa.

## INTRODUCTION

The life expectancy of women is generally higher than that of men. Among men, the highest mortality rates are related to violence, road traffic accidents and chronic illnesses. On the other hand, women present the highest mortality rates related to non-fatal chronic illnesses, and they are also more inclined to seek health care as they observe signs and symptoms which may affect them throughout their lives.<sup>1</sup>

Therefore, longevity is slightly differently for men and women. However, when affected by chronic illnesses, both groups require care provided by others in higher or lower numbers.

The need for physical, affective and financial assistance leads elderly people to leave their independent life behind to live with their respective families, particularly from age 80 onwards.<sup>2</sup>

In today's world, the increasing number of elderly people brings into focus the need for providing care for this group, which involves providing high quality family support, as this is fundamental to reaching this stage of the life cycle. Whenever an elderly person feels well cared for, positive feelings and emotions result, which will reflect in regaining autonomy and the ability to accomplish daily activities. Such feelings reveal that caregiving activities involve more than just the provision of physical care, but also involve psycho-affective needs, such as affection, attention and love, and these needs can only be met through a relationship within a social context.<sup>3</sup>

However, living and caring for a dependent elderly family member may trigger changes which result in an imbalance within the family system.<sup>4</sup> Caring for an elderly person can be difficult, both for the person requiring care and for the caregiver, particularly when the caregiver is not prepared to provide care<sup>5</sup> and/or when family relations are stressful.<sup>6</sup> Such a situation may result in a new internal relationship structure between the elderly person and the caregiver, which may trigger illnesses in family members directly or indirectly involved in the caregiving relationship.

A study conducted in Portugal has identified a potential for illness for caregivers within the family context, which is related to changes occurring due to care provided by one or more family members who live with an elderly per-

son.<sup>7</sup> According to this perspective, a survey conducted in Brazil involving caregivers who are relatives of dependent elderly people has highlighted alterations occurring in their physical and emotional states, as well as an imbalance between activity and rest, and has also alluded to the endangerment of the individual, aimed at pointing out the need to provide quality of life not only for elderly people, but also for their respective caregivers.<sup>8</sup>

Within the family context, women usually play the role of caregiver because this is secularly considered to be a predominantly female role.<sup>9</sup> Bibliographic studies support this idea by highlighting the fact that women are primarily responsible for caring for elderly people in the home. These women are usually wives, daughters and granddaughters between the ages of 40 and 60 with low levels of education, whose main activity is performing household chores.<sup>10-11</sup>

By presenting daughters as the main caregivers of elderly mothers, in addition to characteristics specific to the mother-daughter relationship, the literature exposes the relevance of restructuring these relationships according to the care required.

There is currently a lack of Brazilian studies based on a sociological approach involving care of elderly people aged 80 or over.<sup>12</sup> Therefore, the following questions have guided this study: how do daughters feel about caring for their elderly mothers? How do daughters become aware of their elderly mothers needs? What are their expectations while caring for the elderly person? Hence this study was aimed at understanding the care provided to dependent elderly mothers, according to daughters' perspectives.

The knowledge gathered from this study can contribute to providing high quality care in which elderly mothers' needs are fulfilled in agreement with daughters' perspectives. This can also be reflected in teaching, research and care which involve family dynamics related to caring for elderly mothers.

## METHODS

This is a qualitative study based on the Social Phenomenology perspective of Alfred Schütz, which aims at understanding the care provided to dependent elderly mothers according to daughters' perspectives. For this

purpose, the following key concepts have been isolated: life-world, intersubjectivity, reciprocal perspectives, knowledge records, social action and classification.

Ten caregiving women with dependent mothers were involved; men and elderly caregivers did not participate in this survey because, although they met the criteria for inclusion, they could not be interviewed for physical and/or psychological reasons. All participants were selected through home visits with elderly people in Primary Health Care Units located in a city in Minas Gerais state, Brazil.

The caregiver daughters involved were aged between 42 and 75 years old; these women combined caring for elderly mothers with their duties related to their respective families. Only one of them worked outside the home. The daughters involved in this survey cared for mothers diagnosed mainly with Alzheimer's disease who were aged 80 years or over. Their statements were collected through recorded interview and all of them signed an Informed Consent Form. The following questions guided this survey: how is the experience of caring for an elderly mother? What do you expect while caring for your mother?

All statements were collected from July to August of 2011, in the elderly peoples' homes and at a time selected by the participants. Once all questions were answered and the study objectives were achieved, the interviews were ended. The participants were identified with the letter F (code for 'Daughter' in Portuguese), followed by the Arabic number related to the sequence in which interviews were conducted (F1 to F10).

The organization and comprehensive analysis of the phenomenon in question was performed according to the methodological requirements recommended by Social Phenomenology scholars, which are:<sup>13</sup> a thorough reading of each statement aiming at extracting the overall meaning of the experience of daughters who care for elderly mothers; gathering significant aspects of each statement in order to create concrete categories – objective synthesis related to different meanings of an action derived from each person's experiences; categorical analysis aiming at comprehending the "reasons to" and the "reasons why" for the actions performed by these women; and discussion of the results accordingly to the Social Phenomenology of Alfred Schütz and other references related to this theme.

This project was approved by the Human Research Ethics Committee of the University of São Paulo School of Nursing (EEUSP), under protocol number 1041/2011.

## RESULTS

Based on the perspective of daughters who care for dependent elderly mothers, it was possible to comprehend that the context of meanings related to this group was exposed accordingly to their current and evolving life experiences – reasons why – represented by the categories: "caregiving relationship" and "home care implications". Regarding how they reflect on the care provided – reasons why – these were exposed through the category "care for maintenance of life".

### Caregiving relationship

Caregivers' statements refer to an ongoing concern regarding the mothers' loss of autonomy in performing activities of daily living. Daughters must meet the needs of their dependent mothers within a caregiving relationship characterized by permanent attention and concern: *It is almost like looking after children [...] it requires increasing attention and concern from us* (F2); *I care for her, I'm concerned about her. I feel uncomfortable when I go out and leave her in someone's else care, even if this is a reliable person, I'm still concerned [...], because my mother is a totally dependent person [...]* (F3).

Due to the dependency related to care provided to mothers from daughters, social roles have been reversed within families. This means that the person who was the former family caregiver – the mother – now requires the care of a daughter who used to receive her mother's care or had her children looked after by her mother: *she cannot be alone, so I am stuck! But this isn't a burden to me because she used to look after my son when I was at work and now it is my turn! I care for her* (F8); *[...] I live with her [...], I spend my whole day preparing meals for her [...], I must be patient* (F10).

### Home care implications

Caring for elderly mothers at home has implications for the daily activities of daughters. This results in significant physical, psychological and emotional strain. On a daily basis, this caregiving relationship requires ongoing changes according to the elderly mother's routine, so the daughter



must permanently adapt to the circumstances related to caring for her mother: *she cannot sleep well so I cannot sleep because of her* (F1); *the day is very exhausting [...], I go to bed around 10 or 11 p.m. [...], should I sleep? She [her mother] walks around the whole time. How can I fall asleep? This is so exhausting!* (F7).

The strain experienced by daughters while caring for their mothers requires the creation of a social support network in order to help them to care for their elderly mothers; this network is usually represented by their friends, neighbors and family members. The lack of this social support results in daughters becoming overburdened because all tasks and needs are focused on the mothers. On the other hand, the existence of such a network can help the main caregiver (in this case, the daughter) to better care for her elderly mother: *I went to my son's house because I was feeling exhausted, beaten down [...]. I also need my daughters' help* (F4); *my sister helps me to bath her [...]. Here, everybody cares for her with so much love and affection. Grandchildren, great-grandchildren, all of them are always around. They help us in caring for her and entertaining her. She loves it!* (F5).

Both caregiving relationships and the implications on home care express the meanings context related to the daily activities of daughters who care for elderly mothers. This context is also highlighted in studies referring to this care, which is the anchorage of expectations exposed by caregiver daughters (reasons to).

### Care for maintenance of life

Maintenance of life is defined as a goal to be achieved by daughters who care for elderly mothers. Despite all limitations imposed by the aging process, daughters respectfully care for their mothers in order to provide the conditions required for maintenance of life: *[...] it is important to care for an elderly person so she won't feel abandoned. This means giving love and affection [...]* (F5); *[...] my expectation is that her health improves or at least become stable. But I know this is difficult to achieve* (F6).

Thinking about maintenance of life can also mean thinking about the end, and this often results in an ongoing search for the preservation of life. Although this fact is inherent to all humans, it is important to point out that the caregiving relationship between daughters and elderly mothers promotes a strong bond of attachment. Within this context, the loss of their mothers becomes a future

possibility, so that they become afraid of this time and hope that such an event can be postponed for as long as possible: *[...] I'm afraid of losing her, that's it! [...]* today, she is still able to move by herself; she doesn't have any physical problems [...]. We are afraid that the time will come when she will begin to fall apart (F3); *[...] we hope she stays with us a little longer [...], we are going to do everything possible for her until the last moment* (F9).

### DISCUSSION

The caregiving relationship between daughters and their elderly mothers occurs face to face; for this reason, this type of relationship is considered as the most authentic among social relations. Within this relationship, the social exchange between contemporary people and a genuine understanding between individuals occurs.<sup>14</sup>

The dependency of the elderly mother draws the daughter close and she attentively cares for her mother, taking into account her current needs. This dependency is related to the fragility frequently observed in elderly people. It also involves the combination of illnesses and disabilities which reduce the capacity of elderly people to adapt to stressful situations caused by acute or chronic illnesses.<sup>15</sup> This is the state in which the individual requires care and/or help to accomplish activities of daily living and includes the lack/loss of physical, psychic or intellectual autonomy.<sup>15</sup>

Therefore, daughters intentionally supply mothers' needs during the provision of care. Such a relationship requires a reciprocity of intentions between caregivers and care receivers. The concept of reciprocity is related to acquiring knowledge. Reciprocal perspectives are typical constructions which translate an object of thought whose aspects are known by everyone.<sup>14</sup> It is important to point out that such reciprocity is based on the intersubjective relationship between elderly mothers and their respective caregiver daughters.

Intersubjectivity refers to the life world, which is also referred to as the social world, where people coexist and live together not only physically and among objects, but also as beings endowed with a conscience that is essentially similar.<sup>14</sup>

It is important to highlight that the authenticity of this relationship is based on the interaction between the individuals involved. Therefore, even when dependent elderly people are involved, they must participate in the caregiving activities performed, according to their abilities.

Dependency caused by the aging process increases when chronic illnesses that result in a role reversal between caregiver daughters and their elderly mothers are present. Within this context, it is important to consider the biographical situation of the individual involved; in other words, the individual holds a physical position – in the exterior time of the social system – and also holds a moral and ideological position.<sup>14</sup> This study confirmed that caregiving activities place both daughters and their elderly mothers into contexts which rearrange the social relationship existing between them.

In the contemporary world, elderly women have been assuming roles never described by any literature or public policies. Such roles have forced active elderly women to support their families financially and also assume care of them.<sup>16</sup> Grandmothers, especially on the mother's side, are considered an extension of mothers. This occurs because they represent wisdom, confidence and protection which enables them to care for people close to them.<sup>17</sup> On the other hand, dependent elderly women assume a different role within the family context.

In this study, this fact was exposed by the daughters who are no longer supported by their elderly mothers – who used to help in looking after grandchildren – and who had to assume the role of caregivers for their mothers and other family members. Daughters do not always react positively to this reversal of roles and some of them experience conflicting feelings, as well as physical and emotional signs and symptoms of stress. At the same time as they provide care and attention, they also complain about exhaustion and the impossibility of taking part in work or leisure activities.

A study conducted with children of parents suspected of having Alzheimer's disease has confirmed that daughters point out feelings of obligation and gratitude as the main reason they care for their parents; however, the care provided was viewed as a burden and they did not feel happy about providing this care.<sup>6</sup> Another study has shown that, because of their intensive involvement in caring for their elderly parent, caregiver daughters could not take part in leisure activities, and this fact increased their level of stress in light of facing daily adversities.<sup>8</sup>

On the other hand, despite having conflicting feelings and even considering their situation as a burden, these daughters do not renounce

their caregiving function. This study showed that even in cases when care must be assigned to other people – even if they are reliable people – daughters often feel insecure concerning the meeting of their mothers' needs. This fact was confirmed by a study conducted with caregiver daughters who concerned themselves mainly with activities related to caring for their elderly parents. In doing so, they neither trust nor want other family members holding their position.<sup>6</sup>

Therefore, caring for dependent elderly mothers involves important implications for daughters' daily activities which are related to constantly changing routines, as well as stress derived from caregiving activities that are often associated with other activities expected of women within the family context.

A study conducted with caregivers of the elderly has highlighted that these women commonly suffer fatigue, sleep disorders and leisure deficits; 66.7% stated they had difficulty falling asleep; 76.7% stated that they could not fall back to sleep after waking up during the night to provide care; and, finally, 56.7% report that upon waking up early in the morning they felt tired due to a sleepless night.<sup>8</sup>

It is important to highlight that women are often more affected by care activities, possibly because they frequently assume stressful tasks such as attending to the elderly person's hygiene, and must also manage household activities.<sup>18</sup>

Taking into account the numbers of activities for which caregiver daughters are responsible, we emphasize the need for a social support network represented by family members to help these daughters in caring for their mothers. By assuming this responsibility, caregivers must accomplish several tasks simultaneously. Building a network of solidarity involving family members, friends, neighbors and health services is a beneficial and desired strategy in order to help them to accomplish this activity.<sup>19</sup>

However, such a network is not always present. It was confirmed in this study and this fact increases the stress of daughters associated with caring for their elderly mothers. Usually, caring for an elderly person is the responsibility of one or two members of a family, who may feel overburdened and alienated from other family members.<sup>20</sup> This fact suggests the need to outline effective interventions and support programs in order to manage caregiving activities and reduce the strain related to them.<sup>21</sup>

The comprehensive analysis concerning the experience of daughters related to caring for elderly mothers reflects the “reasons why” interconnected with caregiving actions. These reasons are found both in the present and past of the caregivers, comprised by knowledge acquired throughout life, which includes the experience related to caring for their elderly mothers. This knowledge is associated with the position held by caregiver daughters within the social world, meaning their biographical situation. Based on this position, each person interprets the world according to their own perspectives.<sup>14</sup>

Guided by their experience in caring for elderly mothers, these daughters see a glimmer of actions being continually restructured according to different situations, which will support other motivations and thus will lead to new caregiving activities. This motivation refers to people required to accomplish an activity which is imagined and has originated from knowledge and the biographical situation of each person.<sup>14</sup>

Considering daughters that are currently caring for their mothers, it is conceivable that they see a glimpse of projects related to the health maintenance of elderly women which also give reason and meaning to their own caregiving activities. In order to achieve such an expectation, a connectivity is required between daily care giving – which is allocated to the home context – and caregiving managed by health services – which is allocated to public policies related to elderly people.

Therefore, actions involving the preservation of elderly women’s lives are related to caregiving within the family context and the caregiving planned and accomplished by health professionals, especially those who work within the Primary Health Care Program.

A study of professional perspectives concerning caregiving for elderly people provided by the Family Health Strategy Program has shown that these professionals strive to supply elderly people health needs through preventive actions and health promotion. However, because of the lack of existence of a social support network within health care services specifically directed to the care of elderly people, these professionals do not consider that their social, psychological and familiar needs are being met.<sup>22</sup>

Even when the care of elderly women is provided both by health services and by daughters at home, it is important to consider that the aging process suggests the possibility of death.

Caregiver daughters react with fear toward this reality, thus their caregiving actions aim at preserving their mothers’ lives as long as possible. A study confirms this fact by identifying that 73.3% of caregivers suffer anticipatory grief regarding the death of an elderly loved one.<sup>8</sup>

The group of categories which include the “reasons why” and the “reasons to” has allowed us to build the characteristics of caregiver daughters’ actions as those which comprise a caregiving relationship reflecting concern for the elderly mothers’ situation of dependency, and this results in a reversal of roles between mothers and daughters. These daughters suffer physical, psychological and emotional stress caused by daily caregiving activities and they require a social support network to help them in these activities. They strive to preserve their mothers’ quality of life as far as is possible.

Therefore, the social action theory proposed by Alfred Schütz has allowed us to translate the care of elderly mothers into an activity accomplished by daughters according to their past, present and future experiences, which make it possible to classify them individually within the social world because they are biographically involved in a dependent caregiving relationship with their elderly mother.

This classification reflects a type of person (elderly mother; caregiver daughter) who lives in the real social world and who performs a typical act. This is the ideal of a person who can never be identical to another person or group and provides the comprehension of men within their social relationships.<sup>14</sup>

Some limitations are found in this study, mainly concerning the understanding of a specific social group comprised of dependent elderly mothers’ caregiver daughters. Therefore, other aspects may be exposed through future investigations related to this theme which can clarify different aspects of the phenomenon currently being studied.

## FINAL CONSIDERATIONS

Home context is defined as a scenario in which caring for elderly women is partially or fully accomplished by family members. Among these family members, women, especially daughters, are the ones who often assume this responsibility.

The mother-daughter relationship is restructured accordingly to the level of dependency and results in a reversal of roles between them. Due to the systematic care required by mothers, these



daughters are constantly exposed to significant physical, psychological and emotional strain, in such a way that they require a social network to help them in this activity. This fact suggests a new dynamic and demand on the family which should be considered by health professionals involved in caring for elderly women.

Due to the affective relationship formerly shared by mother and daughters, as well as the changes in this relationship caused by the caregiving situation required, it is necessary for healthcare professionals to ensure an effective connectivity between both demands presented in order to plan and provide caregiving at home. This connectivity must include the expectations presented by daughters concerning caring for their mothers, which involves the maintenance and preservation of life for as long as possible.

For this reason, healthcare professionals must support families in developing actions to promote the health of elderly people, aiming at providing a high quality of life during the aging process. In addition, essential support must be provided to families facing the possibility of death, which is inherent to the human condition.

The problems associated with caring for elderly mothers were exposed in this study through a point of view focused in the intersubjective dimension inherent to caregiving actions. This perspective, based on social phenomenology, has allowed an appreciation regarding the universe of attitudes, reflections and affection associated with the mother-daughter relationship, which is guided by face-to-face meetings and mediated by reciprocity of intentions.

Therefore, the Social Phenomenology of Alfred Schütz has allowed us to comprehend the aspects involved in providing care to elderly mothers according to the caregiver daughters' perspective, and this may result in reflections which can lead to success within the following fields: teaching, practices and public policies directed towards the care of elderly people.

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