

# Family Caregivers: Nurses' Perceptions and Attitudes

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## Abstract

**Background:** The care of dependent people is an increasing concern in our society. Informal care is typically provided by close family members who act unselfishly and with generosity of spirit. In Spain family care remains the dominant form although there is a movement towards models that combine both professional services and family support.

**Aims and Objectives:** To explore nurses' social representations and perceptions regarding the informal caregivers of dependent people.

**Design:** Qualitative research based on focus groups using the domains of knowledge, image, and attitudes.

**Methods:** Nursing professionals from different care fields participated in discussion groups. Data were evaluated using discourse analysis.

**Results:** Nursing professionals have empiric knowledge about the role of informal care, and they are aware of how hard this task is and that caregivers' physical and mental health can be adversely affected. Nurses are in favor of family caring, but they are also concerned about caregivers' isolation and the lack of support and resources for long-term care. Their evaluation of the caregiver role is usually positive, recognizing their steadiness, dedication, continuity, and sacrifice for the dependent person. Family caregivers need more information and train-

ing. Nurses are willing to help caregivers and conscious of their need to be listened to, psychologically supported, and emotionally unburdened.

**Conclusions:** There is a need for greater awareness among professionals, particularly nurses, of the ways in which the caregiver can be seen as a subject who also needs care.

**Relevance to clinical practice:** A model of comprehensive care must attend to the caregiver. Barriers to this include lack of time, deficient teamwork, and preeminence of the biomedical model. Nurses require specific training to improve their work related to the education and counseling of the caregiver.

**Key words:** Informal care, family nursing, social representations, nurse-family interaction, caregivers, community nursing.

## Introduction

The care of dependent people is an increasing concern in our society. In Spain, *dependency* is defined in the *Law concerning Dependency* as a permanent state in which people need significant assistance and/or help with their activities of daily living (ADLs). Dependency can be due to the absence or loss of physical, mental, or intellectual capacities. (LAAD 2006). Informal care of dependent persons at home is a common practice in the countries of the European Union (Viitanen 2005).

According to the *Libro Blanco de la Dependencia* (the White Paper on Dependency, produced by the Ministry of Labor and Social Affairs) *informal care* is defined as care given to a person in need unselfishly and with generosity of spirit. These are principally close family members but may also include persons with no relationship or obligation to the dependent person other than friendship or being a good neighbor (MTAS 2004).

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Although both elderly people and their families want care for dependent people to be provided at home, there is an increasing number of those who feel that the Administration should be more proactive and that families should not assume this responsibility on their own (Duran 2002). Long-term care (LTC) is sometimes highly complex; it is necessary to have adequate training to provide it correctly – this is recognized by most of those who provide care – and LTC must be provided with the supervision and support of professionals (MTAS 2004).

Most dependent people require LTC. This situation led to creation of the *Sistema para la Autonomía y Atención a la Dependencia* (System for Autonomy and Dependency Care). It covers individuals needing LTC, those with moderate and severe disability with respect to their ADLs, and individuals with the combination of disease, dependency/disability and social disadvantage (LAAD 2006).

## Background

Ideally, nursing professionals should be involved in the supervision of basic care given at home. Nurses are trained to provide comprehensive care to patients; this includes attention to their environment. However, health professionals usually focus their attention on the patient without considering the problems that might exist in his or her family environment. In many cases they are not even aware of family issues (Delicado *et al.* 2004). It is worth noting that the health team's lack of interest is sometimes perceived by caregivers. This was seen in a study on primary care in Toledo; only 25.4% of the interviewed caregivers thought that health teams showed any interest in them as caregivers (Vallés *et al.* 1998). Ideally, when assessing the patient's needs, the needs of the rest of the family should also be determined, and the most affected family member, usually the main caregiver, should be supported.

The necessity of working with the family is made clear in numerous ways. For example, the health team is charged with the task of prevention. They should use home visits to explore the family environment, determine the impact of providing care on the family, and detect caregiver burnout early on. The team should support the family, discuss the disease and its prognosis, guide the patient's care, and connect the family with available support social networks (Acton & Kang 2001, Cuesta 2008, Zabalegui *et al.* 2008).

Only recently have informal caregivers been recognized as health agents with whom it is essential to

work in a collaborative and coordinated way. Informal care has become a subject of research and analysis among health professionals, particularly in the past decade. The most important developments have taken place in the fields of geriatric nursing, palliative care, terminally ill AIDS patients, and Alzheimer patients (Delicado 2003). In Greek hospitals, it is a common practice to use family members as unpaid labor to compensate for nursing shortages; the staff considers such contributions necessary (Sapountzi-Kepra *et al.* 2008).

In order for nurses (and other health professionals) to develop a greater interest in caregiver training, support, and prevention services, there must be recognition of the importance of the caregiver's work, its repercussions, risks, and the role of nursing supervision (Torres *et al.* 2008). The way in which these two groups – nurses and caregivers – see and evaluate each other is a crucial factor in forming expectations for their relationship.

It can be difficult to determine the nature of knowledge that does not derive from personal experience. Each society establishes its own rules for the correct ways to think and conceptualize reality; these rules are valid within that society. Social representations are defined as a form of practical and social knowledge used to capture, interpret, and reconstruct reality (Valencia & Elejabarrieta 2007). Social representations are a specific form of knowledge based on common sense. They describe creative and functional processes and designate a type of social thought.

Understanding social representations relating to caregivers may uncover possible areas for improving the interactions between nurses and caregivers. This, in turn, may improve the quality of life for dependent individuals and their families. These interventions might include training, resources, support, programs targeted at caregivers, appropriate interaction with social workers, and interdisciplinary teamwork.

Better coordination between informal care and formal services guarantees that the family can continue to provide care. When caregivers feel supported, they continue their care for longer periods of time (Rodríguez 2002).

Health and social service professionals (doctors, nurses, social workers) play an important role in the care of dependent people and their caregivers. Changes and adaptations should probably be made in their practices and professional training; they must learn to share responsibilities when faced with

problems that have multiple facets – biological, psychological, social – and that require mobilizing community resources. They need to share their professional knowledge with those who actually provide the care on a day-to-day basis. Health professionals need to educate caregivers so they can be more effective in their caring role (Beaver & Witham 2007).

The objective of this study is to explore the social representations and perceptions that nurses have about informal caregivers of dependent people in the domains of knowledge, image, and attitudes.

## Methods

### *Design*

Qualitative research using focus groups.

### *Subjects studied and sample*

The subjects were nursing professionals who were in contact with family caregivers of dependent people in the town and province of Albacete, Spain. To recruit participants we enlisted the cooperation of key informants (nurses in different care settings) to search among their co-workers potential participants for one of our focus groups. Nurses were enrolled if they fit the profile of one of the focus groups (see below).

### *Formation of the focus groups*

To capture the heterogeneity of nursing professionals and explore diverse perceptions of caregivers the sample was composed of seven different focus groups. The seven groups were differentiated by the following criteria: experience in home care and family work, variety of clinical work, age, and gender. Gender was felt to impact on nurses' socialization toward the care of others.

The groups themselves were homogeneous with respect to professional experience and involvement in home care. Each group was diverse in terms of gender, age, and work background.

### *Composition of focus groups*

Groups 1 and 2: Nursing professionals in primary care who are involved in home care plans.

Group 3: Nursing professionals with little or no professional experience; this was defined as less than two years of experience.

Group 4: Nursing professionals with extensive professional experience; this was defined as more than 5 years of experience.

Group 5: Nursing professionals with professional experience in a variety of areas (e.g., geriatrics, occupational health, mental health).

Group 6: Specialist nursing professionals with professional experience in home care.

Group 7: Specialist nursing professionals without professional experience in home care.

### *Data collection*

The focus groups took place in a setting (a social and cultural center) that was familiar to the nurses but not associated with the professional work of either the nurses or the investigators. Eight participants were invited to each of the discussion groups; between five and seven people actually attended. All of them provided written consent to participate in the study. Meetings lasted from one and a half hours to two hours. The information was recorded with the previous consent of participants. All discussions were led by a researcher who provided some direction to the discussion. Another team member participated as an observer. The opening questions were: How do you see family caregivers of ill, old, and dependent people? What is your opinion of them? What kinds of relationships do you have with them? Attempts were made at different times to redirect the debate in order to meet the objectives of the investigation.

### *Discourse Analysis*

The focus group data was analyzed following recommended guidelines for qualitative research. When the focus groups were completed, the recordings were transcribed. For the purposes of analysis, the speakers' discourse was deconstructed by making a tabulation of the information contained in the text. This table was used to construct a report that incorporated what the speakers said as well as the researcher's interpretation of the text and its context (Ribot *et al.* 2000). Quotations were chosen which reflected the key themes of the study: knowledge, image, and attitudes of nurses towards caregivers of dependent people. Coding was triangulated: two members of each team analyzed text, looking for consensus whenever there was a difference regarding categories. The text was structured by themes and interpreted within the nurses' context (professional, health, and socio-cultural) in order to under-

stand the discourse. The report was given back to the participants in the focus groups for their comments on the interpretation of the research team. Participants accepted the final report of the elaborated discourse.

## Results

### *Caregiving is a very important task*

In their description of those who care for dependent family members, nurses highlighted the importance of their work. It was essential, complex, and a tough job:

*If the family is not constantly on top of a drug-addict, following them every single day of the treatment plan, you simply can't accomplish anything with these patients.*

*Children won't allow anyone but their mothers to touch them.*

*There comes a time when the lone caregiver simply gets burned out.*

Nurses also spoke approvingly of the quality of work done by caregivers:

*No one could do a better job than she does. [...] Before we ask her to do something, she has already thought of it and done it well. And you see this in the patient who is calm and very tolerant.*

### *Nurses' Perceptions of the Family*

Perceptions of the family vary depending on the specific characteristics of the household; some nurses, especially those who visit patients in their homes, see the family – most importantly the caregiver – as essential to the treatment plan.

*Ok. We rely a lot on the caregiver.*

*We really have to count on the families since they are the basis for everything else.*

However, things are different when nurses talk about families of inpatients. Opinions in this case differ. Some nurses see families as necessary but not indispensable; when there is no family around, the nurse has to assume all responsibility.

*You tell them: Look if you can't do it, we'll take care of the patient. Don't worry about it. And when the patient is alone, we take care of him or her. But it's easier for us when the family is around.*

### *Problems that arise with family caregivers*

Nurses also noted the problems that arise when families care for dependent people:

*They told us that there were two caregivers who shared the work. But the first one criticized the second and visa versa. [...] There is often a good deal of conflict among family caregivers. When you speak to both sides of the family, you sense that they are not on the same page.*

Nurses also noted cases of family caregivers who neglected geriatric or mentally ill patients.

*They abandoned him, and we had to call in the family. We warned them that if they didn't show up, we'd take them to court for neglect.*

*You notice that visits become less and less frequent.*

While nursing professionals generally value family dedication to caregiving, sometimes they see the family as a problem:

*We met with the family, and it seemed as if they didn't understand the patient.*

Nurses recognize the fatigue associated with this tough physical, mental, and emotional work. This is true for both inpatients and home care patients followed by the health centers:

*Half of our caregivers are under treatment with anxiolytics.*

*The hours are long. [...] And they are terribly isolated.*

*When geriatric patients become disoriented, it is completely overwhelming. It happens a lot at night and families become desperate.*

*They become exhausted. You have no idea what it's like to change someone four times a day, 365 days a year. There are no vacations, no holidays, no nothing.*

### *Nurses' Images of Family Caregivers*

Nurses' images reflect the larger socio-cultural context. The social model of family caregiving – with its gender inequality and perception of crisis – emerges in the nurses' descriptions. The person caring for a dependent family member is a usually an elderly woman and usually who plays this role with devotion and sacrifice for an extended period of time.

*The caregiver is always a woman.*

*Men have neither the training nor the motivation.*

In some cases, this woman caregiver is described in terms of the traditional wife: submissive, self-sacrificing, and diligent.

*Sometimes we cannot fight against what she has been doing all her life. If she has always put his napkin on to eat [...] you are not going to tell her "No, he must do it himself." No way. The woman is his bedrock. [...] Because that's the way it has been all their lives, it is not going to change now.*

Nevertheless, this gender division is not absolute; social progress in the gender division of labor is also reflected in attitudes toward care. This is confirmed by two facts: the shy but real involvement of men in care tasks and the clear crisis in informal care since the traditional housewife – whose exclusive role was family care and housekeeping – is disappearing.

*The vast majority of caregivers are women, but we've also seen men involved. I take my hat off to them!*

*Since we are so used to women, we are surprised when it's a man.*

*Lots of women don't only want to be housewives... they prefer working outside the home.*

Nurses describe caregivers as older people; younger family members hardly get involved in this task:

*Most caregivers are very old people.*

*I don't think young people care for their elderly family... they might go to visit their grandparents for a while so their parents can have a rest.*

#### *Family coping*

Nurses classify families according to the way they face the problems of dependency. Families are grouped as follows:

Families who do a good job of caring: Nurses value dedication to care and, above all, the effort and affection of main caregivers when performing their tasks. These virtues supersede any differences in the economic resources and means needed for the care of dependent people at home:

*The family is what makes the patient's situation different. [...] A better caregiver means a much longer survival.*

*We notice that care is better in the rural envi-*

*ronment than in the urban one and it's because most rural people don't work.*

*The moment you enter the house you know what the family is like, and, sometimes, you leave with a clear impression.... It's nice when you leave saying "My God, how skillful." But other times you leave thinking: "What a disaster of a house!"*

Absent families: Nurses complain about families who neglect their dependent relative. These families disrupt the communication and affection that the patient truly needs. This is also true with institution-alized patients. Despite the best efforts there is no way to compensate for an uninvolved family.

*The moment they leave him/her in the geriatric hospital they basically disappear.*

*Psychiatric patients... have been abandoned by their families. Maybe because they just couldn't cope any longer.*

Families who contract care: The image of families who contract caregivers is diverse, reflecting the varied motivations and involvement among these families. On the one hand, nurses notice detachment in those families who contract caregivers and then do not follow-up on what happens to their relative.

*You find all kinds of things, families who just pay... and then never turn up again.*

On the other hand, the image of the paid caregivers is not very flattering. Nurses think they are only motivated by money and they lack affective commitment and continuity. Care offered for sale is not very good quality care:

*There are lots of people hired to care for patients. It's a mixed bag – usually the care is quite a bit worse because they are just out to earn a bit of cash.*

*There are two types of paid caregivers: [there are] the ones who are responsible and do their job well. You feel they can help... And then there are the ones who think the nurse is the one who has to do all the work and their role is just to keep an eye on us.*

Shared care and family conflicts: Shared care or, more precisely, situations where the caregiver does not live with the dependent person (a common occurrence) are considered sub-optimal for good quality care:

*When care is fragmented, it's bad business. Of course, people need rest, but our experiences with this have not been good.*

**Caregiver competence:** Caregivers are assessed as more or less competent according to two factors: collaboration and learning capability. From the nurse's point of view, several qualities and attitudes can make caregivers more competent and better providers of care. These include:

- Continuity: *"He/she is always there with the patient, wholeheartedly."*
- Ability to learn: *"They are very alert when they are being taught. Even when they aren't asked to, they learn by observing."* *"They pay a lot of attention to how you treat patients [...] to all the details: the mattress, the protection."*
- Previous training and initiative: *"I have met family members who understand completely how to provide care; they are well trained and know when the patient needs to be admitted to hospital."*
- Motivation and commitment: *"Yes, you can tell whether it is vocation or not. There are people with no inclination for this work."* *"Men have neither the training nor the motivation."*

On the other hand, certain factors explain bad quality care:

- The advanced age of many caregivers limits their ability to understand and remember very specific and technical tasks: *"Old people who can't read and are extremely busy..."*
- Lack of experience, especially in men and younger people: *"They haven't done anything like this in their entire lives and they can't do anything, not even changing the urine bag when it is full."*
- Added to the above factors are insecurity and fear: *"I won't be able to do it."*

Nurses also point to the families who feel overburdened, live with emotional distress and anxiety, find it hard to accept the situation, and lose their patience. These situations lead to caregiver burn-out.

#### *Nurses' attitude towards family caregivers*

Nurses' attitudes towards family caregivers oscillate between a need to collaborate with them and a responsibility to care for them.

Their attitude towards the primary caregiver varies depends whether there are one or several caregivers. In general, nurses consider it important to identify one caregiver who is the point person and acts as link between the nursing staff and the rest of the family. Nurses also get involved with the family when there are several caregivers who cannot agree on basic matters.

*With certain diseases you can't be explaining the treatment plan to each and every family member. The team must identify a point person and explain things carefully to that person."*

*"If everybody does things the way he/she wants, we need to intervene by talking to all the family members and acting as mediators."*

This question brings up a number of issues: Do nurses need families? Do the caregivers need nurses? What does the nurse offer? What kinds of relationships are being created? Let's move on to identify attitudes such as collaboration, empathy, and avoidance and to describe the main activities of the nurse with the caregiver.

Through their descriptions, we see that the general attitude of nurses is a predisposition to teach caregivers how to care for the patient and listen to his or her demands. This teaching involves measures to protect caregivers from injuries, emotional overburden, stress, etc.

*Caregivers also need to be cared for. They need health personnel and institutional support to help them a bit.*

*Caring for the caregiver is essential.*

*Most of the time, the main thing for them is to see you as someone attainable, approachable, human.*

Nurses carry out numerous care activities with patients who are bedbound, paralyzed, or dependent. When doing home visits, follow-up and hospital rounds, nurses perform specific activities designed to help caregivers. The kind of activity depends on the patient's needs, the caregiver's needs, and the nurse's abilities and attitudes.

The most common activity is to provide information and training. Information is given about the disease as well as the care needed to avoid complications, crises, risks, and how to adapt to the situation in the degree possible.

*Teach about the disease, how not to lose*

*one's patience. [...] We start slowly and put special emphasis on treatment adherence.*

*Teach the family about how to provide care. They are misinformed and when you give them complete information, explain it, and tell them "We do it this way for this reason" they understand and do just fine.*

Adapting teaching to a family's particular needs and aptitudes is very important. Nurses point out that they are working with a population suffering from multiple learning barriers – advanced age, low educational level, and other limitations:

*What we frequently do - and works really well - is to prepare the medication bags with individual doses.*

*When you are going to take care of the scab, the caregiver stands by your side and you explain to him/her: "The sheet should not lie flat. Now look, this is how we do the drying."*

Less frequently, nurses listen and provide psychological support:

*And also listen to the difficulties. At home they know what resources they have. Sometimes we have to contact a social worker in order to mobilize a few resources.*

*When the patient dies, we try, we telephone to see how they are, or visit them; we have a psychologist in case we notice pathological grief.*

*Family members of mentally ill patients are first informed about the problem their child has, then they are told that they are not to blame.*

These types of services are not always documented. This makes us wonder if work with caregivers is really given its due importance.

*The main caregiver must be identified. The whole team must know who that person is.*

*It is very convenient to have this written down because then you know what has been already explained, what you need to tell them, and what needs emphasis. I think this is extremely important.*

Attitudes depend upon the patient's health problem, the work environment, experiences made on home visits and the nurse's own professional training and work experience. For example, those who

work in home visit teams, because of their experience, training, work methodology, available time, and types of situations they handle (terminally ill, mentally ill, paralyzed patients, etc.) are professionals who exhibit a spirit of collaboration with caregivers. They are in the habit of attending to and caring for families. The home care teams place a priority on caring for the primary caregiver.

*We do home visits and we have no time limits there. We arrive and have time, which we don't have at the hospital, to do training, patient care... The phone doesn't ring, nothing disturbs you, and you are there just for the patient and the caregiver.*

## **Discussion**

Several surveys carried out among the elderly and their caregivers coincide in the fact that families are given an important responsibility with the care of a dependent individual (Valderrama *et al.* 1997). It is taken as a given that sons and daughters have to care for the elderly as a moral duty based on reciprocity and filial love (INE 2010).

The *Law for the Promotion of Personal Autonomy and Care for the Dependent*, published in Spain in December 2006, clearly acknowledges the responsibility of the state for the care for those who can no longer care for themselves (LAAD 2006). The law also provides support to families and dependent individuals in the form of various material and economic resources as well as personal and institutional services. Durán (2004) points out that in a democratic society, which supports equity in the distribution of tasks, benefits, and opportunities, the individual impairments suffered by dependent patients must be assumed collectively. Otherwise, an important number of women – the primary caregivers – would be forced to limit their hopes for an autonomous life. This would particularly impact their possibility of full participation in the social and work worlds. The end result would be an increased risk of poverty at retirement (Delicado 2003, Vitatanen 2005).

Several socio-cultural factors account for the *a priori* assignment of women to the care for dependent and sick people. Beliefs and values limit caregivers' expectations, restrict their autonomy, and condition them not to ask for help or seek support. Koslosky (1999) has described some of these beliefs: the importance of *family*, *hierarchy*, and *per-*

sonal favors.\* These beliefs are deeply rooted in health and public health professionals (MTAS 2004). Nevertheless, these ways of thinking are themselves in flux as new expectations have appeared. It is more and more accepted that professionals, and/or paid caregivers, are involved in care and support for ADLs.

Nurses recognize both the importance of caregivers' work and their problems. Nonetheless their image remains a bit stereotyped (Casado *et al.* 2008). Caregivers are still considered to be users who lack knowledge and demand advice and support by health professionals. Nurses who work in primary care and/or do home visits have a more realistic and fair knowledge of caregivers. They also collaborate more and carry out more nursing interventions with the caregiver than do other care sectors (Gómez & Martos 2003).

Within the Spanish imagination, the quality of informal or family care is associated with the degree of relationship between the caregiver and the dependent person (e.g., partner or daughter), female gender, and an almost exclusive and sole dedication on the part of the caregiver (Duran 2002; García Calvente 2004; Casado *et al.* 2008). These are the preferences expressed by recipients of care and by the nurses in this study. Nurses also prefer dealing with a single main caregiver. This reflects the priority they give to professional efficiency which is seen as more important than other desirable social values such as gender equity (distributing the burden of caring by involving other family members, e.g. younger people and men), prevention of burnout and other negative health repercussions for the caregiver, and caregiver quality of life. These are all extremely common concerns among people who care for dependent relatives (Delicado 2003).

Existing literature suggests that the most frequent activities of nurses with the primary caregiver are to teach about the disease and to provide training in the care needed by the patient (Gómez y Martos 2003; Beaver & Witham 2007). These actions are essential in the comprehensive programs of caregiver support that are being established in some health care services. They are also the main demand of caregivers (Nieto & Bolaños 2003, Zabalegui *et al.* 2008).

Nurse – and other health and social services professionals – also consider other nursing activities as very important: initial assessment of the patient and his/her family, follow-up with the caregiver to iden-

tify signs of burnout or other problems, psychological support, active listening to the caregiver's complaints, offering support resources, and the possibility of taking part in caregiver programs, including support groups (Mejido *et al.* 1999, Faison *et al.* 1999, Mourente *et al.* 2001, Garrido 2003). Primary care physicians who visit elderly people may alert others to possible deterioration in family caregivers, especially spouses (Sewitch *et al.* 2006).

Comprehensive programs of caregiver support are still uncommon in Spain. Nurses are not the only ones who have created them; professionals from other social services such as psychology and social work have been involved in caregiver support. Both counseling and support groups have enabled families and primary caregivers to develop better emotional, intellectual, and psychological coping mechanisms (Mourente *et al.* 2001, García Calvente *et al.* 2004). According to Weman (2004), nurses understand the importance of cooperating with family members of elderly people living in nursing homes. In general, nurses recognize the need to improve communication with the caregivers for the elderly dependent and other chronically ill patients; they also want to assist them with making decisions (Bradway & Hirschman 2008, Whitlatch 2008, Beaver & Witham 2007).

Nurses show great concern and worry about the lack of resources, such as day hospitals, home care nursing service, temporary stays, to support caregivers and dependent individuals. In the last few years, the idea has taken hold that caregivers are a social group toward which government agencies should direct welfare programs, support services, and specialized professional practices (Delicado *et al.* 2004; Greenberger & Litwin 2003). This movement developed in Spain following the 2007 implementation of the *Law on Dependence*. By July of 2010, nearly a million people had registered for evaluation and some 600,000 had received a covered service or benefit; 51% received economic benefits for their role as family caregivers (IMSERSO 2010). Most services have a relatively low degree of coverage. However, the number of people served in residential facilities has increased over the last decade, while resources such as home care, adult day care centers, tele-care, and others are expanding (IMSERSO 2009).

While it is difficult to prevent caregivers from being overworked, health care professionals can provide them with resources (Izal *et al.* 2003). This is common for the nurses who work within a holistic

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\* Translator's note: *familismo, jerarquismo, personalismo*

model of family care. However, if family caregivers are an important resource in the health care system carrying out everyday tasks that nurses would otherwise be performing, then specific staffing policies for reducing the burden on the family should be introduced (Sapountzi-Kepra *et al.* 2008).

In this study, nurses cited several limitations to their ability to more efficiently support caregivers: lack of time, lack of resources, and lack of recognition of the caregiver as patient. They also see their own ability to provide psychological support and establish a helping relationship as limited. This supports the findings of a national study that found 100% of health and social service professionals considered specific training in psychosocial and behavioral aspects of care as necessary in order to appropriately attend to the needs of caregivers (Izal *et al.* 2003).

Despite these limitations, health professionals are trained to support caregivers. This was confirmed by Izal's study of Spanish health and social service professionals' ability to care for elderly dependent people (Izal *et al.* 2003). The authors found that social service professionals frequently felt that caregivers' demands are not within their area of responsibility, but health care personnel did not share this viewpoint. It would be useful to discuss which groups should be responsible for caregivers and then to define the roles of each group *vis-a-vis* caregivers in a way that emphasizes interdisciplinary work.

## Conclusions

Nurses have empiric knowledge of informal care and its importance. They recognize the quality of this work as well as its negative impact on the health of caregivers. This impact is not described in terms of specific diseases, but rather expresses itself in prescription drug usage, fatigue, and emotional despair. Nurses are aware that caregivers lack specific training. In addition, they stress their own need for written instructions for post-hospital care.

The predominant image of the caregiver is that of an older woman who works in isolation, sacrificing herself. Her only roles are housework and caring for others. However, other images appear in some of the nurses' discourses: male caregivers, women who also work out of the house, paid caregivers.

Nurses have a generally positive view of informal caregivers. They value personal effort and willingness to serve. It is clear that the family is important to the patient's recovery; our subjects critiqued the way hospitals have traditionally treated

families. The caregivers of mentally ill patients face special difficulties in communicating with patients. They need specific support by specialized professionals.

The most common attitude seen in our study was nurses' willingness to teach caregivers and to listen to their demands. Collaboration, availability, and empathy all supported proper patient care. Nurses primarily see caregivers as a resource. Yet at times the caregiver becomes an individual needing the care and attention of the health team.

The most common activities performed by nurses for caregivers were the provision of information, training about home care, and providing advice on relations with the patient. Listening and psychological support are less frequently reported. However working with care-givers is not specifically recognized within nursing diagnostic and therapeutic protocols.

Nurses' attitudes and activities with caregivers are influenced by lack of time, hospital workload and organization, and the different health care models (traditional biomedical model versus community-oriented comprehensive care model). Interaction with caregivers is favored by working in the home with families. Nurses want specific training and teamwork in order to improve their care. Moreover, they propose that nursing documentation be systematized in such a way as to provide written evidence of their actions with caregivers; this would make follow-up care easier.

## Relevance for clinical practice

The present study has several implications for clinical practice. We emphasize the following recommendations:

- Health authorities should be more attentive to the needs of caregivers. Health policies and resources could be better focused in the areas of home care and the relationship of the nursing professional with family members of dependent people and other caregivers.
- Our findings can help nursing professionals to be more aware of the needs and demands of caregivers of dependent people. This awareness can assist them in finding appropriate responses within their professional competencies and in coordination with an interdisciplinary health team. Caregivers need enough training to provide care correctly. Professionals must support

them with appropriate resources and adequate supervision.

- Academic authorities must update the training of nursing professionals to reflect social changes (an aging population, increasing numbers of dependent people, changes in family structure and family roles) and to incorporate new competencies that needed to address these changes. These competencies include communication, training, and nursing interventions in complex social and health situations.

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