The Craft of Care: Family Care of Relatives with Advanced Dementia¹

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ABSTRACT

Family caregiving is attracting more attention from policy makers and service providers but managing a chronic condition in the home is a very complex activity and usually remains invisible to health care professionals. In this article I describe “The Craft of Care,” a category that emerged in qualitative analysis in a study of family care of patients with dementia. Its purpose was to identify strategies family caregivers used in the home to care for their relatives. I collected data from interviews with 18 caregivers and 2 health care professionals, and from participant observation in caregivers’ support groups and homes. I used constant comparison analysis after entering data into QSR Nvivo. Caregivers craft care by using three strategies: they create ruses in care, a language to communicate, and spaces and devices for caregiving. They sustain the humanity of the patient in the midst of a condition that tends to destroy it.

Key words: Caregiving, dementia, family care, grounded theory.

INTRODUCTION

The care of people with chronic illnesses at home is impossible without family care, which is the major health care resource (Jewson, 1993; Francisco del Rey, & Mazarrasa, 1995; Nettleton, 1995; James, 1998; Bond et al., 1999; Muñoz Gonzalez et al., 1999; Nolan et al., 1999). In Europe more than two thirds of chronic care is provided by the family (Nolan et al, 1999) and a study in the United States found that 22 million adults are informal caregivers to people over the age of 50, 80% of whom are family members (The National Institute of Nursing Research, 2001). The economic, social and therapeutic benefits of family care have been extensively documented (de la Cuesta, 2004). Caregivers who reside with

dementia patients are critical in the ability to keep these patients at home rather than in institutions (Schneider, 1999). For health care professionals it is evident that the presence of a family caregiver makes a positive difference in home care (Cozad Lyon, 1997); due to the emotional ties and affect in the relationship between the patient and the caregiver, family care is better than professional care (James, 1999). While family caregiving is attracting more attention from policy makers and service providers (Ryan et al, 2004), managing a chronic condition in the home is a very complex activity that requires more than medical care and this complexity usually remains invisible to health care professionals (Strauss et al., 1984). Home care demands that caregivers develop increasingly complex knowledge and skills (Schumacher et al., 2000) because, as disease advances, complicated management increases (Wackerbarth, 1999).

The difficulties faced by families caring for a relative with dementia, especially low income families, have recently been acknowledged (Marks & Sykes, 2000). Dementia patients can present caregivers with extraordinary management difficulties (Brody, 1990) because of their unstable and unpredictable behavior (Gubrium, 1991). As their cognitive deterioration increases, family members no longer know who their relatives are, and their gradual loss of mobility makes them highly dependent (Mace & Rabins, 1997; Marks & Sykes, 2000). Caregivers of dementia patients must solve numerous and varied everyday problems. For example Rundqvist (1999) found that the principal problem for caregivers of patients with dementia is communication, the ability to interpret their communicative signs and understand their wishes. However, for many caregivers, communication is less a problem than the demands and pressures of care that threaten to overflow their resources (Briggs, 1998). Caring for a dementia patient is “one of the most devastating and challenging

experiences caregivers can endure” (Butcher et al, 2001 p. 33) and the burdens of caring for such patients is greater than in other chronic conditions (Conde Sala, 1998; Ory et al., 2000; Ericson et al., 2001;).

The richness, diversity and complexity of caregiving situations in real life are not well known (National Institutes of Health, 1999). In particular, caregivers’ capacity to create strategies and to solve problems has not been well documented in the literature. Recent literature addresses this lack of understanding of the nature and essence of family caregiving of dementia patients, grounded in caregivers’ experiences (Butcher et al., 2001).

In this article I describe “The Craft of Care,” a category that emerged in qualitative analysis in a study of family care of patients with dementia. I found that such care is defined as informal, an unfair and limited way to define it, as this article will show. The aim of the study was to identify strategies used by Colombian family caregivers to manage the demands of caring for relatives in advanced stages of dementia at home. As dementia caregiving figures strongly in descriptions of family care (Manthorpe et al., 2003), I selected advanced dementia because it confronts caregivers with the greatest physical and emotional demands (Collins et al., 1993). In addition, home care for a relative with advanced dementia is common in Colombia but not well addressed in the research literature. Most literature on caregivers and caregiving comes from developed countries (Opie, 1994) in which chronic patients and their caregivers have access to formal support and policy supports such services (Ryan et al, 2004). When impairment becomes too great, moving to a residence or sheltered accommodation is not an option in developing countries because of few formal support networks (Klaasen et al., 1996; Alfonso et al., 1999) and

lack of access to services (Bowes & Wilkinson, 2003). In Colombia family care still a private, family trouble, and not a state, public trouble (de la Cuesta 2001a). National surveys are nonexistent and the scant literature about dementia family care is not included in international data bases (de la Cuesta 2001b). However, there is evidence that in Colombia, as everywhere else, family care is intense. For example a descriptive study of family care of 78 children with cerebral palsy in Medellín found that caregivers were women who devoted between 13 and 24 hours per day to this care (Alvarez, 1997). There is no public formal support for dementia patients and their caregivers in Colombia and private support is insufficient and fragmented. Caregivers depend mostly on the solidarity of relatives, friends and neighbours because they are left to their own resources.

METHOD

A qualitative study based on grounded theory principles and methods was conducted in Medellín, Colombia. Based on Symbolic Interactionism, grounded theory focuses on people in a continuous process of giving shape to their worlds (Blumer, 1969). Grounded theory is regarded both as a research methodology (Schwartz & Jacobs, 1979; Morse & Field, 1995; Mayan, 2001; Morse & Richards, 2002) and a style of analysis (Strauss, 1987). As such, it generates theory from experiential data (Glaser & Strauss, 1967; Strauss 1987; Strauss & Corbin, 1998) and provides researchers with a systematic way to analyze data collected naturalistically (Charmaz, 2000).

The Ethics Committee of the Faculty of Nursing, Antioquia University, Medellín, Colombia, approved the study. I treated data confidentially and protected anonymity of participants during the research process and communication of findings. I alone had access

to the data and pseudonyms were used in presentations. As a registered nurse I felt that I could deal with unpredictable patient care situations during fieldwork. Participants agreed to take part in the study in an informed way. They knew the aim of the study, who financed it, what their participation involved, and how the results would be disseminated.

Participants knew that they could decline to answer any question and withdraw from the study at any time. Data from relatives with dementia was not actively sought as the participants were caregivers; however, during data collection some sick relatives were present; due to their cognitive impairment, family caregivers consented on their behalf.

Data collection took place between September, 2000 and March, 2002. The University of Antioquia Neurosciences Research Group facilitated access to potential participants. Three of those contacted did not to take part in the study. Two caregivers did not want to talk about caregiving as they had recently admitted their relatives into a residence, and access to a third caregiver was denied. A purposeful sampling strategy was initially employed to select long-time caregivers of highly dependent relatives with advanced dementia. The 18 participants were primary caregivers and included 15 women and 3 men; 10 were 51-75 years old, 5 were 25-50 years old, and 3 were younger than 25. Ten of the women were daughters; the others were wives, sisters, or nieces. The men were two sons and one husband. Participants' level of education varied: 6 did university studies, 6 finished secondary school, 3 finished primary school and 3 did not finish primary studies. Seven participants had been caring for their relative 7-8 years; 9 for 2-4 years; and 2 had become primary caregivers less than one year before. Eleven caregivers gave exclusive care or provided care more than 60 hours per week, while seven gave care 20-60 hours per week. Nine of the 18 relatives were suffering from Alzheimer's disease, four had vascular

dementia, four had mixed dementia, and one relative had yet to receive a definite diagnosis of cognitive status. Sixteen were completely dependent on their caregivers as they were at a very advanced stage of dementia. There is no indication that this is a special group of participants, however, contact with the Neurosciences Research Unit could have made them more amenable and accessible to research.

As analysis proceeded, I used a theoretical sampling strategy (Strauss & Corbin, 1998) to reanalyze the data collected to date on what I eventually referred to as “the inventiveness of care,” a recurrent topic during interviews. I redirected subsequent interviews to elicit more information about “Inventing” caregiving, sought additional sources of information, and observed in caregivers’ homes. In line with grounded theory procedures, data collection proceeded concurrently with analysis and ended when theoretical saturation was achieved (Strauss & Corbin, 1998). All together, 22 interviews were conducted with 18 caregivers, and I spent 23 hours of participant observation in 10 homes and 4 caregiver support groups.

Interviews lasted 30-90 minutes; all but one were conducted in caregivers’ homes. The format was that of a conversation with a structure and a purpose (Kvale, 1996). Open interview questions based on the purpose of the study allowed participants to talk about their experience. Interviews began with a grand tour question asking caregivers to describe either a usual day in their lives or a significant day in the care of their relative. Caregivers were also asked to describe caregiving activities and how they managed acute crises. Later in the study, more questions were directed toward eliciting descriptions of caregiving strategies. Interviews were audio taped and transcribed verbatim except for three during which I took notes as they were informal interviews during fieldwork. After the interview,

participants frequently continued to give me information while they showed me their homes or during coffee. These interviews were also social occasions for the participants. An additional six interviews were conducted with two health care professionals working with dementia patients to elicit their views of family caregiving. This type of data is referred to as shadowed data (Morse, 2001), which helps the analyst to identify relevant issues, orient theoretical sampling and contribute to the saturation of categories.

After each interview I recorded field notes on data that were not audio taped; these notes were transcribed and placed with the interview transcript. Field notes were also taken during participant observation and transcribed after each session of observation. The field diary was organized in terms of observational notes, theoretical notes, methodological notes and personal notes (Schatzman & Strauss, 1973).

Constant comparison analysis was used after entering data into QSR Nvivo. I used three types of coding: open, axial, and selective to identify and develop categories, and then to further refine and link them. “Inventiveness, tricks and divining” emerged early in the study as relevant categories. Through selective coding and micro analysis (Strauss and Corbin 1998) I looked for examples of things that caregivers invented, tricks they use, what in fact they divine and what was the purpose of these practices. The search for negative cases enabled me to confirm and to develop categories until their saturation. For instance, one participant said that she did not divine what her sick relative needed but observed carefully her behavior and, through body messages, found out what she needed or wanted to transmit. This data led me to realize that the issue was about communication. Using theoretical sampling, I looked for further data relating to ways of communicating and

analysis led me to conceptualize the strategy of creating a language. I also explored the relationship between ruses and inventiveness and found via negative cases that ruses were in fact creations of the ingenuity. Thus “Inventiveness” became a superior category and the idea of caregivers as makers begun to emerge. As analysis continued, the idea of care as a kind of craft earned its way into the analysis. Categories were saturated when no new and relevant information was found in data. Both the search for negative cases and saturation refined emergent categories, and their names and links changed until they fit in the data. Through development of categories, sorting codes and memos I identify The Craft of Care as the core category.

During analysis, I consulted relevant publications and developed analytic memos. By writing memos I became more aware of the themes in the data, their level of development, and relevance to the research question. The software enabled me to link memos to categories and to have ready access to them. In order to maximize the trustworthiness of findings, they were discussed with participants and, on three occasions, with groups of professional providers with expertise in the care of patients with dementia.

FINDINGS

The craft of care

Participants in the present study commented that “there is no magic formula,” so caregiving is tailored to the person cared for and in fact is “invented.” As one participant said:

“One has to have many clues with them [sick relative]; one has to invent many things.”

Caring for a person with advanced dementia is not a rational process or one that follows any rules. Although dementia is classified by stages, it is not a lineal and orderly condition but rather a complex and disorganized one (Gubrium, 1987). “The disease gets better and worse at the same time” says Bayley (1999, p. 200), Iris Murdoch’s husband and caregiver portrayed in the film “Iris.”

The relatives’ cognitive impairment, uncooperative and difficult behavior, lack of all sorts of resources, and immense caregiving needs created great challenges for caregivers participating in the study. They overcome them with inventiveness that made care possible under adverse circumstances. But caregivers invent care not only for practical reasons, but also as a craft that transforms the sick relative, the material world and the caregiver (de la Cuesta, 2004). To craft is an embodied skill “at building something or making something work in a precise way” (Frank, 2003 p. 251); it is also a creative activity. Caregiving is a craft in the sense that it seeks to respond to needs aiming at restoring health, that is, a craft in an Aristotelian sense. Aristotle distinguished the crafts that seek to respond to pressing needs from those that seek pleasure and leisure; both kinds of craft, according to Aristotle, intend to restore health (Estrada Herrero, 1988). Caregiving of patients with advanced dementia is thus a craft forced by pressing needs; it is unplanned, invented as the sick relative condition evolves.

The study found that, like artisans, caregivers craft care in creative ways (de la Cuesta, 2004) by resorting to the metis, the Greek term for the practical intelligence. This intelligence is related to prudence, the stratagems, ruses and the ability to take advantage of situations; it gives the weak the means to triumph over the strongest (Detienne & Vernant,

1988). The practical intelligence is applied to realities that are unexpected, ambiguous and unstable, all of which typify caring for a relative with advanced dementia at home in Medellín, Colombia. In continuously changing situations “it is required of fertile spirit in stratagems, able to invent a plan each time adapted to the circumstances” (Detienne & Vernant, 1988 p. 133). Indeed, due to patients’ variability, caregivers’ invented solutions are perishable. A caregiver in the study explained that whatever she invented to care for her sick relative “only worked for a few days.”

Ruses of Care

The ruses of care serve as ways to deal with very difficult situations, hidden ways that caregivers discovered or “figured out,” as they sometimes said during interviews. With ruses caregivers fool their relatives, and they related many examples. For instance one caregiver found a way to undress her husband and another worked out how her father could recognize his bedroom:

He took my hands and shook me [not allowing her to undress him]. Then what I did was to make a sort of paste with soap and water in a vase and before I began to undress him I put it on his head so it dripped into his eyes, so while he was trying to take it off, it was mild soap, very mild, I undress him. This method I invented myself.

No, daddy, this is your room.” “No, no, it is not my room.” “Come in and see, where do you have your pajamas?” “In my room.” “Come on, let’s see if they are there.” Then he goes in and we search for the pajamas and he lets me guide

him and realizes it is his room. When he does not allow me to guide him to the room, I take his things out for him to see them, to see that they are his shoes, his clothing.

Caregivers in the study strive on a daily basis both to get their sick relatives to accept being taken care of and to accept them as their caregivers. This can be an arduous task, a task for the caregiver's inventiveness, for their practical intelligence. Care in advanced stages of dementia is not only intimate, as caregivers commented during interviews, but basic; they do everything for their relatives, such as feeding them, taking them to the toilet, dressing them, changing their soiled underwear and putting them to bed. Relatives will not always let their caregivers help them with such activities of daily living, often resisting such care. During interviews, caregivers related situations where they had to deal with stubborn relatives who refuse to eat, take a medicine, or to clean their teeth. They also confronted "catastrophic" situations where the relative got lost in the home and began to cry in despair as he does not know where he is, and rebellion, when the sick relative does not allow herself to be cared for intimately as she feels that her privacy is invaded. In these situations caregivers confront a kind of adversary. During the interview, a participant said she had to convince her mother that she was helping her to care rather than the other way round. With this ruse the participant made an alliance with her mother, who accepted her daughters' caregiving; she was no longer an opponent.

To provide care for their sick relatives, caregivers in the study use many and varied ruses. They invent pretending games and pantomimes, design traps and elaborate tricks. Caregivers invent games and pantomimes, to enter into their sick relatives' world and

prevent unmanageable situations. For instance, when a participant's sick relative gets lost in her home and cannot find her way to a room, the caregiver pretends to be the bus that takes her there, so they tour until they reach the place. Another participant, during the interview, remembers what her mother used when her aunt very obstinately wanted to leave the house to visit the mayor of the city. The arrival of a visitor served, with the help of a pantomime, to sort out the situation; he became the mayor and held a conversation with the sick relative as if she were his colleague. Sometimes what is needed is to deceive and distract the sick relative, so caregivers in the study design clever traps into which their relatives naively fall. For instance, a caregiver explained during a support group that she was able to remove her relative's artificial teeth by giving her chewing gum. As the gum stuck to the teeth, her relative "voluntarily" took the set out, allowing a moment in which the caregiver could clean them. Another caregiver explained during the interview that he convinced his father to go to bed early in the afternoon by putting him in his pajamas, so that he could leave the house early. In other circumstances there is a need to calm or cheer up the sick relative and then caregivers create elaborate ruses that create a climate conducive to care. It might be to read the Bible to the relative as a participant does; singing to him as another caregiver does with his father; or "conversing with her" as a participant relates, "so she [sister with Alzheimer's disease] does not feel sad." Involving the relative in everyday activities is another ruse that supports a caring climate. A caregiver participant asks her mother to help her to tidy up magazines and another involved her mother in sewing:

....I like very much to sew, so when I was going to do it, I bring her with me to the room, put on her favorite music, and seat her near me. As she also used to sew, I said to her "come and help me, I am lost, I do not know what to do." She laughed, took the fabrics, the measuring tape, and played with them, but I

behave like we were both involved in the sewing. Also when I knit, I seat her near me, taking care that she does not fall out the chair, and say “Well, you must help me with this, dear, as I am very tired.” She laughed, took the yarn to play with it, but nevertheless we are sharing.

Thus, the ruses of care are smart ways caregivers invent to provide care for their relatives. They serve to overcome their sick relatives’ resistance, to keep them calm and stable; ruses highlight caregiver’s ingenuity and resourcefulness. They all address relatives’ humanness. For example, data shows that caregivers play with them as if they were children or treat them as the relatives they once knew. In this way the ruses reaffirm dementia patient’s humanity.

The use of smart ways to solve caregiving problems has passed unnoticed in the literature. However, there is some evidence of the use of ruses or tricks by auxiliary nurses to calm dementia patients (Ree-Danahay, 2001) and those used by family caregivers of elderly people to bathe them (Jansson et al., 2001). In the case of neurological patients, the need for stratagems to help the patient recover is well documented (Sacks, 1998; 2002a) but such stratagems are hardly acknowledged as standard procedures that make it possible to care for patients with dementia.

A Language to Communicate

People with advanced dementia do not speak. A caregiver in the study says it plainly:

“..my father does not speak, nothing, nothing, and nothing. He cannot tell what he has but I can figure out many things; thus he gives me meanings and I can get them.”

In spite of relatives' great cognitive and language impairment, study participants communicate with them in significant ways. They transmit to their relatives that they love them and are able to understand their responses; they make them smile, look in particular ways and say words. For caregivers there is no doubt that “a person is there,” as one participant expressed, meaning that regardless of the relative's condition he or she is still a living human being with the capability to speak and to be spoken to, able to transmit and to receive messages. How do caregivers make themselves understood and are able to listen to a person who does not speak anymore? Data shows that caregivers create a unique language, one that only they and their relative understand. But this language is created over time; one caregiver spoke of the difficulty at first of understanding her mother:

The hardest part of dealing with my mother was that I had to supervise her when in the bathroom. “Mum, do you want to pass water? Do you want to move your bowels?” Sometimes she said yes, sometimes no, sometimes said yes and did something, other times did not do a thing...then I said “get dressed” as she was doing nothing. Shortly afterwards again back to the bathroom and half hour later the same, guessing again to see if now was the right moment.

As cognitive impairment increases, caregivers in the study replace and compensate for language losses. By touching the relative, caregivers find out, for instance, where it hurts. A participant speaks of gestures when he concludes the interview by saying that his father

“understands many things, not with the words but by means of gestures.” The gaze, a kind of gesture, is “listened to” by both caregivers and sick relatives. For instance, during one of the interviews I saw how a caregiver and her father speak to each other with their eyes. By looking into her father’s eyes, the caregiver understood that he wanted to join us. She asked him with words if he wanted to come and interpreted “yes” in his eyes. Indeed this nonverbal language is accompanied by a tonal language, the language that transmits sentiments. According to participant caregivers, affection is a sentiment essential to caring for relatives with dementia; they emphasized that everything ought to be done “with love;” the tone of voice is how they transmit this sentiment. But also by tone of voice caregivers persuade relatives to comply with such requests as to get out of the shower or to help in getting undressed. The tone that was expressed during the interviews when caregivers were reproducing conversations with their relatives shows that it conveys orders, requests and love; relatives comply because of the way it is said, not because of what is said. Thus, this new language is made of gestures and tactile and tonal signs that both caregivers and sick relatives emit and interpret.

The data show that with practical intelligence caregivers interpret signs and, with ingenuity, craft ways of communicating that their sick relatives can understand. Caregivers understand their sick relatives by reading the signs that they produce. These signs are sent via the body, a nonverbal language that requires the caregiver’s ability to guess; the job here is basically one of interpretation. Caregivers carefully observe relatives’ behavior, noticing their reactions to things and make connections to find out what the relative is trying to say. Caregivers divine their sick relatives, as one commented during an interview:

I am able to divine [that she's hungry] because she might suddenly start to yawn, then she begins to stretch herself. Then one says "she has pain or she is hungry...when one sees her like this, the way she is right now [restless] and the afternoon is cold, very cold, one can guess right away that she is cold, one has got already the clues, one knows...

Ability to divine is related to visual sharpness of the mind and consists of having worked out a system to interpret signs (Bloch, 1985). Guessing is a mental process "situated between thinking by analogy and the ability to decode signs that link the visible with the invisible" (Detienne & Vernant, 1988).

Caregivers also use different analogies to represent their sick relatives, such as babies, children or patients. A participant sees her father, a 70 year old man with vascular dementia, as a baby with whom she communicates:

...because my father is a baby and a man. One caresses him and gets a response, this is how my father is. At night when I get him ready for bed and he feels heavy, I move the bed and I say to him that I am going to lift him up, I hold him and ask him to hold to me tight, to give me a hug. And he hugs me and sometimes he taps my back.

But the use of analogies also serves a purpose for successful communication. A central element in communication is to "take the role of the other" (Hamilton, 1994). Only by figuratively introducing oneself in the mind of other is coherence in the conversation achieved and the roles in the interaction sustained, for Mead said that this is basic to all social organization (Mead, 1934/1972). Caregivers do not take see their relative as a

particular person but rather the generalized other (Mead, 1934/1972), in which they see their relatives are babies, children or patients. Conversationists point out that the most general principle that specifies interaction in conversation is the design of the receptor; according to this design the use of words, the sequence of the phrases, and the topic of the conversation are adjusted (Wolf, 1988). It can be said that when caregivers give their relatives a generalized identity, they are in fact designing the receptor and therefore striving for a successful interaction. To interpret their relative's signs, caregivers need to mentally "see" someone, a person who needs care. By attributing an identity, the social status of non-person, which dementia patients tend to acquire, is negated (Hamilton, 1994). This invented language keeps dementia patients socially and emotionally alive. By the same token, caregivers' identities are transformed, "I am the mother of my mother" said one caregiver during the interview. Caregivers provide care similar to what parents give to their children, and during interaction their sick relative's identities and their own emerge:

...yes, it is like taking her role (as mother). If she were not sick she would look after me. Now she cannot do that so I have to do it for her...yes, because it is like one becoming her mother, there is a need to cook for her, wash her, change her clothing...

Over time caregivers craft diverse languages and by doing this they express their own identity; Hamilton (1994) says "Communication is possible because there is enough in common" (p.39) To read the signs of the relative's body, caregivers need an analogy, to make sense of themselves, as a participant explains:

...what happens is that every day one is divining; it is like being a mother, a mother that guesses what she (the relative) wants.

Language conveys identities that emerge during interaction. During field work caregivers expressed also that they were like nurses or secretaries as their relatives become completely dependent on them. Language humanizes both caregiver and the sick person. It humanizes caregivers when they divine, as Elias (1998) asserts, “One needs to be human to read appropriately the facial signs of humans” (p. 325). Being “read” humanizes the dementia patient; when he is understood, he becomes a subject. Not without reason is it said that body language, which has no words, is “the most human of all the languages” (Tele Antioquia, 2002).

Creating Spaces and Building tools.

Spaces are of therapeutic importance and caregivers are aware of this:

She is adapted to the home, to the environment.....she does not get lost anymore, not in this moment, but I would not move out with her because in an apartment or in a small house it would be very difficult; it has to be big spaces, a pretty big home (like the one in which they are living) and I think this (having space) has served for her to last so long.

Keeping a relative with dementia at home until the end, as caregivers participating the study said they wish to do, requires creating a physical home environment that permits both patient care and family life. The study found that as the patient condition evolves, caregivers interact with their material world and change it by adapting the home and household goods to particular conditions. In this caregivers show that they are true artisans of home-made devices, equipped with ingenuity and resourcefulness, able to see the

therapeutic possibilities in everyday spaces and objects. The transformation of this material world is described in detail elsewhere (de la Cuesta & Sandelowski, 2005); here the focus is on the strategy of creating spaces and tools for caregiving.

Creating spaces

From the moment caregivers recognize the nature of dementia and the progressive deterioration associated with it, they began the work of accommodating the home for the well-being and care of their relative. The process is that of putting the home “to the service” of the sick relative, as a caregiver said during the interview. This implies redesigning the home and the human activity within the spaces of it. For instance, the bathroom and kitchen are redone, the relative’s bedroom is reallocated, the patio becomes a place for the relative to rest, corridors are transformed into promenades for the relative to take a walk or even a place where the relative is washed. Caregivers allowed room-based activities to be performed anywhere in the house. A caregiver followed his father around the house to give him his food. Spaces were transformed both by physically altering the spaces themselves and by virtue of the human activities occurring in those spaces, or what urban planners call changes in “land use” (Handy et al., 2002).

All these changes were made to facilitate care or surveillance, but others were directed toward making the home a safe place for the relative with dementia. Caregivers appreciated the risks that an unmodified house posed for these family members, who could simply escape and get lost in the street. They could suffer serious accidents in the home or become trapped in the most amazing ways and in the most unforeseen places, like a participant’s

wife did by trapping her head on the bars of her bed. Caregivers who had to leave their relatives alone, either at night or during the day, had to improvise to ensure a safe environment for them. A caregiver placed an extra bed close to her sister's bed in case she fell during the night. By accommodating the home, caregivers craft an environment that supports and enables care.

Building the tools for caregiving

...at the beginning she (sick relative) ate normally, with a spoon, then she begun to deteriorate and start to close a bit her lips, then we invented this.... When we try to feed her, she immediately closed her mouth, so we invented one of this little flasks that have something to take (like a teat) then we feed her with this and she took it.

Like true artisans, caregivers themselves make the tools to care or reinvent existing objects because they cannot afford to buy them or because they are not available. Caregivers modified beds to make them more similar to hospital beds, i.e., raising them to facilitate caregiving and attaching rail-like devices to prevent relatives from falling out of bed. They transformed plastic chairs into wheel chairs by building platforms with wheels and attaching devices to prevent their relatives from falling over or out of these chairs. Caregivers made their own straight jackets to restrain relatives' risky movements, used plastic soda bottles to clean nasogastric tubes, and made their own feeding bottles to get past the sick relative's closed mouth as the caregiver did to feed her sister. Caregivers also use every day objects in innovative ways, for instance baby alarms to monitor relative's

sleep, syringes to give fluids or a bicycle to rehabilitate the relative as a participant did for her mother:

They told me that after the third stroke my mother would not be able to walk again. So I took my son's bicycle, which is small, and put it upside down. I tied her sick foot to the pedal and pushed with the other pedal. Her foot stayed this way (she makes a circular movement with her hands) and I tell her to "go on, go on, and go on, go on, and go on." My mother achieved strength in her leg. I also added a bag with two or three little stones. As my mother gained more strength, I put more sand, and more sand, and more sand. I made two weights of sand for my mother.

By relating to objects in new ways, caregivers also refashion them; objects are not fixed entities but products of social life. The meaning of an object resides not in the object itself, but rather is produced in interaction with it (Blumer, 1969). A caregiver filled the drip plastic bottles used in dialysis with water to make a water mattress to prevent pressure sores. In the hands of these caregivers, everyday objects became technological objects in the domain of caregiving (Sandelowski, 2000).

Family caregivers create hybrid places or almost-homes (Albert, 1990), that is they create spaces for therapeutic work with the home, to accommodate the changing trajectory of dementia and to transform the home into a place where all family members can live safely and, at the same time, care for their sick relative (de la Cuesta & Sandelowski, 2005). By doing this they keep the dementia patient at home to the end, in fact, they accomplish their

aim of providing the “best care” for their relatives, i.e., care provided within the home (Ericson et al., 2001).

DISCUSSION

Dementia is a devastating chronic condition with an unpredictable and unstable course. Caregivers must cope with the long-term and disabling physical and behavioral problems (Butcher et al., 2001). The purpose of this study was to identify strategies caregivers used in the home to manage the demands of care of relatives in advanced stages of dementia. Caregivers showed caregiving to be a craft and themselves to be artisans. Their caring strategies sustain the humanness of the relative with dementia, which is identified with quality in dementia care (Ryan et al., 2004). Thus, a major contribution is caregivers’ reaffirmation of dementia patients’ humanity in the midst of a condition that tends to destroy it. A previous study found that family caregivers define and redefine the person with dementia (Clarke, 1999); this study furthers this finding, as it shows that caregivers see their sick relatives with advanced dementia as babies or children as a way to provide care for them. The artisanship of caregiving is about crafting new family relations and therefore identities. If we consider the body as an expression of social practices (Turner, 1992) caregivers take care of their relatives’ social presentation, they sustain their individuality, their dignity, to keep their human attributes by interpreting their feelings, translating them for those who do not their special, unique language. By doing this they give their relatives an altered identity, that is a human being with limitations who sometimes resembles a baby, a child or a very sick person. Caregivers therefore sustain the social body of their sick relatives and not only the physical one, they preserve the persona and by so doing they become their parents and also their nurses. Indeed, it has been

acknowledged that the increasing complexity of home care transforms caregivers into health care personnel, able to perform complex tasks with great skill (Rhodes and Shaw, 1999). Caregivers in this study took on roles that they did not anticipate and their caring relations transformed their sick relatives back into lovable human beings; they achieve this against great odds, the great decay and deterioration that advanced dementia produces. Their care is crafted amidst adversity.

Caregivers in the study learned their trade as they practiced their craft, as other artisans do, knowledgeable about the effects they want to produce (Estrada Herrero 1988). However, the capacity to craft care and its contribution is not seen in the literature. Caregivers tend to be depicted as overburdened, with little preparation to care for their relatives, and in need of support (de la Cuesta, 2004); their resourcefulness and inventiveness are unnoticed or taken for granted. However, to invent care is not new to nursing; in the XIX Century, professional nursing was related to finding ways to apply doctor's orders (Sandelowski, 2000). Neither is creativity in disease an alien concept. The capacity for adaptation in neurological patients and the methods they employ to survive is documented in the literature (Sacks, 2002b). In chronic conditions, creativity is needed to sustain care: "when a disease does not cure, people with creativity find hope in other ways" (Boss, 2001 p. 116). Caregivers in this study highlighted other ways to care.

"The conceptualization of family caregiving is in its infancy," affirms Ross et al. (2001, p. 349). Survey research has contributed knowledge about types of caring activities, their duration and intensity; however, such emphasis might well contribute to a narrow definition of family caregiving (National Institutes of Health, 1999). Caregivers, however, define care

in broader terms, pointing out, for instance, that it begins long before the execution of a given caring activity (National Institutes of Health, 1999). Caregiving transcends the execution of tasks and places as research studies have shown (de la Cuesta, 2001c); it involves a diffuse relationship (Abel, 1990) in a context of rich family relations with a common past (Morgan & Laing 1991; Rutman 1996); family care continues after the relative leaves the home (Ross et al., 2001; Van den Brink, 2003). A recent study enriched the definition of caregiving activities by uncovering three categories: socio-emotional, proxy, and instrumental caregiving with the general purpose of the protection of the care recipient's self (Aberg et al., 2004). By taking the caregivers' point of view and grounding findings in their experience, the present study also contributes to the expansion of family caregiving conceptualization.

It has been pointed out that the quantitative emphasis in the dementia family caregiving research literature has limited the capacity of health professionals to fully understand the caregiving experience (Butcher et al., 2001). This is relevant as the literature has pointed out how important it is for family caregivers to be acknowledged by professionals and have their work supported (McGarry & Arthur, 2001). The findings of this study also might contribute to health care professionals' appreciation of family caregivers' craft; it should lead to a new regard for how they create health resources and innovative ways of caring. Community nurses can pass on to other families what they learn from family caregivers. Nurses themselves have a long history of innovation and improvisation in care (Sandelowski, 2000). Health care practitioners' awareness of caregivers' craft will assist them to assess caregivers' needs, and support them in their creative efforts, especially those who lack the inventiveness of the caregivers interviewed in this study.

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