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PREVIEW

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**“Doing the distance”: The experience and meaning of
long-distance caretaking**

Herman, Charlotte Marie, Ed.D.

The University of Nebraska - Lincoln, 1994

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PREVIEW

"DOING THE DISTANCE"
THE EXPERIENCE AND MEANING OF
LONG-DISTANCE CARETAKING

by

Charlotte M. Herman, Ed.D.

A DISSERTATION

Presented to the Faculty of
The Graduate College at the University of Nebraska
In Partial Fulfillment of Requirements
For the Degree of Doctor of Education

Major: Community and Human Resources

Under the Supervision of Professor John Dirkx

Lincoln, Nebraska

December, 1994

DISSERTATION TITLE

"DOING THE DISTANCE"

THE EXPERIENCE AND MEANING OF LONG-DISTANCE CARETAKING

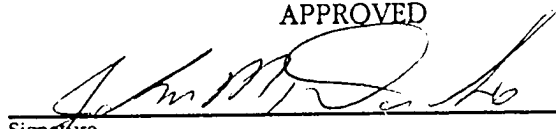
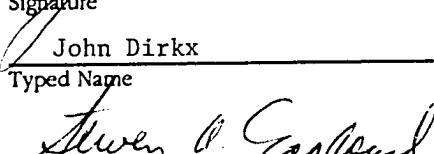
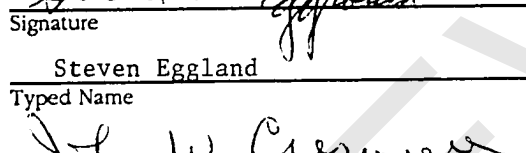
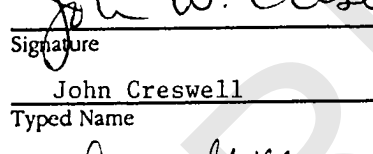
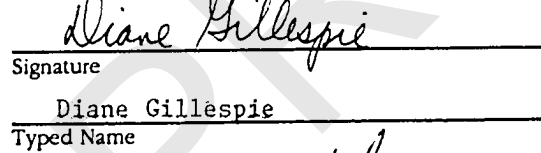
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Charlotte M. Herman

"DOING THE DISTANCE"
THE EXPERIENCES AND MEANING OF
LONG-DISTANCE CARETAKING

Charlotte M. Herman, Ed.D.

University of Nebraska, 1994

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The need for caregiving in the home has increased because people are being discharged from hospitals while they are still sick. Sometimes individuals in need of care have to rely on a relative who lives at a distance. The scholarly literature concentrates on caregivers who live with or in proximity to the care recipient; however, the caretaker who lives a distance away from the care recipient has received little attention.

The purpose of this study was to explore long-distance caretaking, and to gain understanding of the ramifications of that caretaking. The study utilized life history research methodology to give voice to the stories of three distance caretakers. Long interviews were conducted with women who had cared for their widowed mothers who lived at least 3 hours away. The care recipients lived alone in their homes located in small rural towns or, in one case, a suburb of another large city. The care recipients died in their homes while being cared for by their daughters who were their long-distance caretakers.

This study identified five important thematic areas which represent the phenomenon of "doing the distance." They are based on an interpretive cross-case

analysis. The themes include the areas of adjustment, family and mother-daughter relationships, separation, and finally, what was learned through the experience.

This study provides new knowledge of distant caretaking and has possible implications for education, policy, and research. Implications for nursing curricula and community continuing education are based on concepts of incidental, expressive, and instrumental forms of learning. The policy implications relate to providing care, to gender, and to employment. Research implications center on gathering stories from caretakers with different work flexibility, educational levels, and financial capability. There is a need for research on distance caretakers with different cultural and ethnic backgrounds, and a need to study males who are distant caretakers. Finally, investigation is needed on the issues of separation and loss as they are related to the mother-daughter filial connection and family dynamics.

PREVIEW

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CHAPTER I

INTRODUCTION TO THE STUDY

Context and Research Problem

Every day people spend time, effort, and resources caring for parents, relatives, or significant others. These caretakers provide the care recipients with physical, emotional, spiritual, and financial assistance. The trend toward caregiving at home is growing, due in part to diminishing third-party payment for care in institutional health care settings, and to the reality that elderly and disabled people with health problems frequently need long years of care. Yet, as more home care is needed, fewer persons are available to provide such care. Several demographic factors have contributed to the declining numbers: increased longevity, divorce, and geographic mobility, along with a steady reduction in fertility levels which has reduced family size and therefore the number of potential caregivers. Particularly significant are geographic mobility, which restricts access to and contact with older parents, and rising divorce rates, which affect financial and personal support for both the care recipient and caregiver.

Studies of caregiving have focused on the individual who lives in proximity to the care recipient. The issues which are discussed most often in this literature revolve around (a) who provides the support for the care recipient; (b) the effects of caregiving on the on-site caregiver; (c) caregiver reactions; and (d) relationship issues among parents, children, and other family members. Caretaking at a distance has remained largely unexamined; however, studies of caregiving in local proximity to the care recipient suggest a need to investigate distance caretaking as well.

Local caregivers have reported symptoms of stress and feelings of being burdened and overwhelmed. Caregiving restricts personal life, social life, employment, and vocational opportunities and is a particular problem for daughter caregivers (Brody, Dempsey, & Pruchno, 1990; Litvin, 1992; Stoller, Forster, & Duniho, 1992). Researchers argue that stress for the female caregiver stems from a more intimate and complex emotional relationship with her mother, such as nurturance issues and other emotional variables which place women in more complicated and intense caregiving situations (Mui, 1992).

Given the nature of the problems identified for caregivers who live in local proximity to the care recipient, it is incumbent on us to better understand the role of the long-distance caretaker. It seems reasonable to suggest that the issues which are prevalent for the on-site caregiver may present even more serious problems in a distance caretaking situation. Such research becomes particularly important in light of the trend in our society toward families' assuming responsibility for their elderly members (Phillips, 1989). The task is to provide research information which will assist with bridging the gap between understanding of on-site caregiving and long-distance caretaking. In response to this need, health care educators must consider incorporation of long-distance caretaking information in their curricula.

Statement of the Purpose

The purpose of this study was two-fold: (a) to explore long-distance caretaking and (b) to provide some understanding of the ramifications of that caretaking. It focuses on the meaning of long-distance caretaking as well as the role of the caretaker as it is perceived and experienced by the participants.

The long-distance caretakers in this study were all daughters of the care recipients. Each of the caretakers was employed full time as either a teacher or nurse during the time she was caring for her mother. Each caretaker had to travel at least 3 hours to reach her mother's home; distances ranged from 200 to 1,000 miles one way. Two of the care recipients lived in rural towns, and one lived in a suburb of another large metropolitan area.

The care recipients were women who had been widowed for at least 15 years. During the care period, all were in their late 70s, and all were living in their homes. The care recipients were all terminally ill when the participants started to fill their roles as distance caretakers. Each of the care recipients spent some time in a hospital setting during her illness; however, each died in either her own home or in the home of her daughter who was the caretaker.

Research Question

The grand tour question for this study was: What did it mean to be a long-distance caretaker for your mother? Seven questions were utilized to reach an answer to the grand tour question:

1. What was life like for you as you were growing up?
2. How did you come to be your mother's caretaker?
3. What was life like for you as you filled your role of caretaker?
4. How did you negotiate your responsibility of being your mother's caretaker?
5. What was the nature or quality of the relationship you had with your potential support providers?
6. If you were to do it all over again, what would you do?

7. Would you describe your distance caretaking experience in the form of a central metaphor?

Definitions

Long-distance caretaker. A person who lives at least 3 hours away from the care recipient who is her or his parent or significant other. This person assists or provides the care recipient with physical, emotional, and environmental care (Herman, 1992).

Caregiver. A person who lives with or near the care recipient and who either assists with or provides physical, emotional, and environmental care for that person (Herman, 1992).

Care recipient. An individual who lives in her or his home and who is receiving care from the long-distance caretaker (Herman, 1992).

Life history. A research method used with informants in order to understand circumstances that contribute to present and past events. It involves in-depth interviews with selected individuals who represent a topic of interest. Subjects are guided by the researcher to recount certain aspects of their lives in detail so that patterns surrounding a particular theme can be identified (Roberts & Burke, 1989).

Delimitations and Limitations

The study is narrow in scope in that it focuses on three long-distance caretakers in metropolitan areas in the central United States. The number of participants was small because the study utilized a process which involved in-depth interviewing of participants after they had completed their roles as distance caretakers.

Researcher bias was addressed through the incorporation of peer evaluation, member checking, and the researcher's rechecking data (Marshall & Rossman, 1989). Researcher bias may be considered insider knowledge and as such can be an asset to the research process (Taylor & Bogdan, 1984).

Although the data are not generalizable to all long-distance caretakers, they do provide direction for further research. The data are subject to other interpretations; however, the transferability of the data rests with the individual making the application. The data are particularly useful for understanding the meaning of the lived experience of caring for and about mothers who live at a distance.

PREVIEW

CHAPTER II

REVIEW OF THE LITERATURE

There is a significant amount of information available on caregiving by individuals who live with or in proximity to the care recipients. This research, developed primarily by health care or social science professionals, has described care given by family members to elderly recipients. It has addressed primary caregiving consequences and their ramifications. The issues discussed most often for on-site caregivers revolve around (a) who provides the support for the care recipient; (b) the effects of caregiving on the on-site caregiver; (c) caregiver reactions; and (d) relationship issues between parents, children, and other family members. The caretaker who lives at a distance from the care recipient has been left largely unstudied. In order to demonstrate the nature of the caretaking relationship and provide rationale for the importance of the research presented here, an illustrative picture of the available on-site caregiving research follows.

Who Provides the Support for the Care Recipients?

Family members, especially adult children, are the major support providers to the impaired elderly. Women generally interact more frequently with family members since they see themselves, as do others, as emotionally closer to their parents than to their male siblings (Horowitz, 1985). The literature, however, indicates that both daughters and sons provide care (Smallegon, 1985).

Brody, Litvin, Hoffman, and Kleban (1992) revealed that daughters outnumber sons as caregivers 4 to 1, and daughters experience more stress than sons in comparable positions. Brody and colleagues also reported a sense of aloneness for

unmarried women serving as caretakers. The marital status of the caregiver is significant since single divorced and widowed children are expected to have more time to interact than those caregivers who are married. Adult daughters perceived caregiving as a stressful experience; however, sons tended to be less negatively affected (Horowitz, 1985). Sons often referred to caregiving as having no associated problems. Interestingly, the spouses of these sons were very involved in the caregiving (Brody et al., 1992; DeWit, Wister, & Birch, 1988; Frankel & DeWit, 1990).

Stoller (1983) revealed that married caregivers provide less assistance than their single counterparts. Sons who had full-time employment provided less care than daughters who had full-time employment. Daughters with full-time employment provided care regardless of that employment.

Research by DeWit et al. (1988) focused on the extent to which proximity of adult children influences social contact between elders and their offspring. It revealed that demographic trends (e.g., low birth rates, living large distances away, etc.) have substantially altered social contact between the elderly and their adult children. Children see their parents less; however, there is a durability in the bond between the child and the parent which lasts throughout the life span. That is to say, they do not stop caring, in an affectionate sense, because of distance (Schoonover, Brody, Hoffman, & Klebon, 1988).

Effects of On-Site Caregiving

Numerous studies have addressed the effects of caregiving. Cantor's (1983) work looked at married women caught between the needs of a parent and the needs of their own families. Stoller et al. (1992) explored the impact of employment and family responsibilities on the assistance provided by an adult child who responds to

the needs of a parent or parents. Allan (1988) analyzed the relationship between family solidarity and the sense of moral responsibility and obligation felt by adult children for their parents. Allen found that when the child experiences a feeling of increased moral obligation for a parent, there is also a feeling of increased guilt.

The literature has examined the caregiving experience as it relates to feelings of burden. Caregiver burden is the physical, emotional, social, and financial problems that are experienced by caregivers. Burden is the negative impact of the events, activities, and feelings caused by changes the caregiver undergoes to provide care (Braithwaite, 1992). Caregiving tasks that confine the caregiver temporarily or geographically are the best predictors of burden (Montgomery, Gonyea, & Hooyman, 1985). Braithwaite (1992) viewed burden as related to events and activities associated with negative caregiving experiences, such as losses of employment and financial well-being. Burden is also related to such things as the caregiver's income, age, and caregiving tasks performed.

Caregiver Reaction to the Effects of Caregiving

Powerlessness of the family-member caregiver and the need to assume the roles formerly filled by the sick individual have been shown to significantly affect the caregiver's stress level. These caregivers experience pressure on the job, chronic fatigue, anger, depression, low morale, and poor health (Davidhizar, 1992). Other research has revealed caregivers' concern about personal physical symptoms. The most frequent diagnosis for caregivers--hypertension--can be related to a high stress level. Caregivers take more medications and are less satisfied with social and family networks (Baillie, Nordbeck, & Barnes, 1988; Hail, 1988; Robinson, 1989).

The feeling of powerlessness can be associated with a less positive future outlook for both caregivers and care recipients (Rakowski & Clark, 1985). Related to powerlessness is the negative attitude some caregivers have toward asking for help. Robinson (1989) indicated that caregivers often do not ask for help since they equate it with failure, and as a result, their functional health and attitude are sometimes negatively affected. Robinson also postulated that helping caregivers to improve their outlook may reduce feelings of stress, and reducing stress may improve future outlook.

Future outlook can be negatively affected when a care recipient is placed in a long-term facility. When the care recipient is moved to such a facility, the caregiver may experience guilt, anger, and depression which are a part of their early bereavement process (Hail, 1988; Robinson 1989). Sometimes a phenomenon referred to as dual dying occurs in which the care recipient's intellect deteriorates while physical health remains relatively good; in effect, the person dies first intellectually and later physically. The caregiver responds with feelings of guilt, anger, and depression as part of the bereavement process which is related to the series of losses before the actual physical death of the care recipient (Jones & Martinson, 1992).

Relationship Issues

Children often live far away from their parents, and this geographical distance can be related to the quality of the bond between parent and child. In most cases, however, the child-parent relationship appears to override geographic, socioeconomic, and developmental changes (Brody, 1985; Moss, Moss, & Moles, 1985). Moss and Moss (1988), focusing on reunions between elderly parents and adult children, found that love and affection are generally the most important reasons for reunions. In

addition, an intergenerational bond exists in which neither the child nor parent wishes to consider the possibility that any one reunion may be their last, so important personal matters are often not discussed (Moss & Moss, 1988).

The Schoonover group (1988) addressed sibling issues which arise when an elderly parent needs help. Among these issues are the equitable sharing of responsibility, communication, and disagreement over their parents' needs. There may also be feelings which come from unresolved sibling rivalries. Some caregivers feel guilt because they cannot do more to relieve the sibling providing the help. A feeling of guilt may also be caused by the competing demands of the caregivers' own families and careers. The recurrent theme in the Schoonover research is the inability to respond to the parent's needs in a timely fashion or on a regular basis because of family obligations, financial restraints, or both. Additionally, some siblings have feelings of being cut off and left out of decision making and feelings of being uninformed as to the parent's day-to-day condition (Schoonover et al., 1988).

The literature addresses other relationship issues such as the care recipient's difficult, demanding behavior and inability to communicate (Baillie et al., 1988; Blazer, Hughes, & George, 1987; Braithwaite, 1992; Robinson, 1989). Caregiver research has also examined effects of duration of caregiving, as well as losses of social support from friends and social activities, and losses of leisure time, freedom, privacy, and sleep (Braithwaite, 1992; Hogstel, 1990).

Summary

The family plays an important role in providing care for the elderly in their homes. Female children of care recipients provide the most support; however, both female and male caregivers provide emotional support, financial aid, and linkage

services. Sons are less likely to help with medical, social, or environmental services. On-site caregiving has negative physical, emotional, and financial effects. Yet, for the caregiver, there are unwritten norms which indicate that asking for assistance is unacceptable. The caregivers refer to themselves as powerless. When negative effects occur and persist in a caregiver, they must be considered.

In light of the literature on caregiving and the nature of the caregiving relationship for the on-site caregiver, there is reason to be concerned about what might be happening to the long-distance caretaker. Distance caretakers who are predominantly female have been left largely unstudied even though they are important providers of care, especially for the elderly. This study provides initial research regarding the experiences of three female distance caretakers who cared for their dying mothers. It provides insight into the meaning of providing care while residing hundreds of miles away from the care recipient.

CHAPTER III

THE METHODOLOGY

Research Design

Life history or life writing has been utilized by historians, sociologists, and psychologists, although anthropologists can make the strongest claim to this methodology (Langness, 1965). It is being increasingly used by social science and health researchers who are interested in the qualitative paradigm (Smith, 1994).

The personal contextualization of a life makes life history methodology valuable; however, it is not always clear what life history is. A life history is more than an autobiography. Life history methodology focuses on what has happened to a single person:

. . . caught up in a stream of historical events not of his or her own making, adapting to those events and, most critically, giving them meaning. It includes memories strung along a time-line that, when reviewed each of us calls "my life" which is a construct that vanishes when we die. (Hughes, 1994, p. 5)

Robertson (1983) stated that life history is a kind of oral story told by the person being studied and put together by the researcher. Life histories are exploratory research, generally a compilation of life span narratives which are told by the living participant (Dyk, 1938; Simmons, 1942).

Often the research subjects are chosen not for unique characteristics, but because they are people who need a voice (Robertson, 1983). Life history or life writing is grasping the context of a life as it is lived. Geiger (1986) presented life history design as an extensive record of a person's life told to and recorded by

another, who then edits and writes the life. Finally, Roberts and Burke (1989) described life history as a qualitative data collection research method used with informants in order to understand circumstances that have contributed to present and past events.

Allport (cited in Watson, 1976) perceived life history as a commentary on a person's viewpoint as that person understands it. Allport thought that if a researcher wanted to know what someone felt, experienced, or remembered, the best way to attain that information was to ask him about it. Langness (1965) viewed life history as an extensive record of a person's life told to and recorded by another. This life record is edited by the researcher and written as though it were an autobiography. In contrast to Langness, Mandelbaum (1973) viewed a life history as an account of a life, completed or ongoing, with a principled selection process determining what is included.

Mandelbaum (1973) indicated that life histories emphasize how the participants cope with life experiences and societal expectations and are concerned with the dynamic and adaptive aspects of a life. Mandelbaum's research considered the quality of a person's life and provided a way to understand direct meaning for change. The objective of life history methodology is to mirror each participant accurately within his or her environment, society, and culture. The reader then might come to understand, to a degree, how something happened or felt. The test for accuracy is to have the participants read the material and to say, after they have read it, "That's me" (Simmons, 1942). Earnest (1992) wrote about life histories as "the landscape for a subject's orientation to his or her needs, frustrations, and potentials" (p. 12). Life histories are a way to understand the past, evaluate actions, and plan for the future.