

Scripps Gerontology Center

Scripps Gerontology Center Publications

Miami University

Year 1995

Caregiving paths, patterns, and
perspectives

Kathryn McGrew
Miami University, commons@lib.muohio.edu

Ohio Long-Term Care Research Project

**CAREGIVING PATHS,
PATTERNS, AND
PERSPECTIVES**

Kathryn B. McGrew

November 1995



Kathryn McGrew is Assistant Professor in the Department of Sociology and Anthropology and a Fellow with the Scripps Gerontology Center at Miami University, Oxford, Ohio. With a background in social work, Dr. McGrew has focused her research and teaching in the areas of mental health and aging, long-term care, and family caregiving. She was Principal Investigator for a study funded by the Ohio Department of Mental Health to examine the mental health treatment and services of nursing home residents with major mental illness. Most recently, she was the Clinical Review Coordinator for *New Initiatives in Home Care Service Delivery*, a project funded by the Administration on Aging. Dr. McGrew's report, *Daughters' Decision Making about the Nature and Level of Their Participation in the Long-Term Care of Their Dependent Elderly Mothers* (1991) was published by the Ohio Long-Term Care Project at Scripps Gerontology Center and provided much of the conceptual framework for this report of both spousal and filial caregivers.

This research was funded by a grant from the State of Ohio, Board of Regents, Ohio Long-Term Care Research Project. Reprints available from the Scripps Gerontology Center, Miami University, Oxford, OH 45056; (513) 529-2914; FAX (513) 529-1476.

Caregiving Paths, Patterns, and Perspectives

Kathryn B. McGrew

**Scripps Gerontology Center
Miami University
Oxford, OH 45056**

November 1995

Abstract

This qualitative study of the caregiving experiences of twenty-three caregivers—daughters, sons, husbands, and wives—explored the interaction of caregiver characteristics, caregiving conditions, caregiver attitudes, and caregiver behaviors on the caregiving path over time, to identify the shared and variable qualities of that interaction across caregiver types.

Two in-depth interviews were conducted with each participant and verbatim transcriptions of the tape-recorded sessions were the data for analysis. A coding process developed by Anselm Strauss (1987) facilitated the analysis.

It was found that caregivers interviewed demonstrated a conscious pursuit of objectives related to the well-being of the self as well as the care receiver. Objectives often had their foundation in marital and filial relationships. Several features distinguished spousal from filial caregiving. Spouses worked consciously to preserve the fundamental nature of the marital relationship, while filial caregivers pursued a reframing, or sometimes, restoration of the filial relationship.

Caregivers identified a multiplicity of factors motivating caregiving. These included a commitment to social standards of behavior and role fulfillment, "natural" responses to crises, being the "only one", and a commitment to family precedent, among others.

Set on the course of caregiving by their multiply-determined impulse to care, the caregivers were endowed with a set of reserves employed to tackle the demands of caregiving. The reserves may be divided into three categories: the strength of the impulse to care, assets, and support. An economy of reserves management became a major dynamic of the caregiving path.

Several implications for long-term care policy are explored. Developed from the premise that the impulse to care is inherently exploitable, an effective public economy of long-term care reserves is recommended.

Acknowledgements

The author wishes to thank the following colleagues for their assistance and support in this project: Bob Atchley, Lisa Groger, Lisa Haston, Cheryl Johnson, Marisa Scala, and Larry Weiss. A special debt of gratitude is owed the twenty-three men and women who gave so generously of their time and themselves as they shared their caregiving experiences.

Table of Contents

BACKGROUND	1
METHODOLOGY	2
Sample	2
Data Collection	2
Data Analysis	3
FINDINGS	3
The Impulse To Care	4
The Pursuit of Objectives	5
The Well-Being of the Care Receiver	5
The Well-Being of the Caregiver	6
The Primacy of the Marital Family	7
Spousal caregiving	7
Preserving the essence of the marital relationship	10
Filial caregivers and the marital relationship	11
Reframing the filial relationship	12
Caregiving as a Slippery Slope	13
Caregiver Reserves	14
Economy of Reserves Management	14
Strength of impulse to care	15
Assets	16
Time	17
Finances	17
Space and geography	18
Personal assets	18
Physical health reserves	18
Mental health reserves	19
Knowledge	19
Skills and experience	20
Support	20
Informal support	21
Spiritual support	22
Quasiformal support	22
Formal services	23
Caregiver resistance to use of formal services	24
Care receiver resistance to the use of formal services	24
The nursing home	25
Use of support groups	25
CONCLUSIONS AND POLICY IMPLICATIONS	26
BIBLIOGRAPHY	29

Background

Although caregiving literature in the past decade has increasingly contributed to our understanding of the characteristics of caregivers, their behaviors, and their attitudes, the literature is poor in studies which contribute to our understanding of how individuals' caregiving patterns evolve over a period of time. How do characteristics, behaviors, attitudes, and conditions interact on the path of caregiving? Furthermore, what are the shared and variable qualities of this interaction between different caregiving relationships, both filial and spousal?

In a recent study of caregiving daughters (McGrew, 1991), there emerged a number of ideas about caregiving meriting further exploration and analysis, and certainly compelling the expansion of inquiry to include (at least) the caregiving experience of sons and spouses. The study, with a focus on daughters' decision making about their participation in the long-term care of their dependent mothers, revealed that the women interviewed responded to the needs of their mothers with a multiply-determined impulse to care and struggled through all caregiving decisions to reconcile that impulse with their thresholds of support, seeking a balancing point of caregiving activity. This struggle was especially evident at the major caregiving shifts: assuming, sharing, and relinquishing care. While seeking decisions they could live with, corresponding to their personally constructed definitions of

"enough", the daughters faced limiting decision conditions that affected the course of caregiving.

The implications of this analysis for further research included a need not only to modify and/or verify the findings through interviews with more caregiving daughters, but also to "test" the ideas with sons and spouses. Using reconstructed histories and a framework of inquiry based upon the findings of the daughter study, the study reported here pursued an in-depth qualitative analysis, across caregiver types, of the interaction of attitudes, behaviors, and conditions on the caregiving path over an extended period of time.

The central questions for study are: What is the interaction of caregiver characteristics, caregiving conditions, caregiver attitudes, and caregiver behaviors on the caregiving path over time, and what are the shared and variable qualities of that interaction across caregiver types?

Using caregiving decisions as both the products of that interaction and the consequent markers of caregiving shifts, the questions were explored through the following focus: How did/do caregivers decide about the nature and level of their participation of their dependent spouses or parents over time?

At the major caregiving shifts: 1) how do caregivers describe their impulse to care or other attitudinal response to dependency; 2) what are the decision conditions; and 3) what are the thresholds of support? How are these reconciled, how are they manifested in caregiving behaviors, and how do they change over time?

Methodology

In her recent book, *Women in the Middle* (1990), Elaine Brody writes:

Although quantitative studies of... patterns of care and of the other [than daughters] actors of the parent-care scene are indicated, qualitative studies from the unique perspectives of clinicians and ethnographers are vitally important. Such studies permit a view of the processes at work within individuals and families. They inform quantitative studies, aid in interpreting findings, point the way to methods of helping, and...present a more rounded picture of matters we now know about primarily from the vantage point of "primary caregivers"..... There is a particular need for longitudinal studies to supplement cross-sectional surveys. People's situations change over time, and it is the trajectory of change that informs us of their needs. (p. 28)

Although the methodology used in this study is not longitudinal *per se*, it pursues a long-range retrospective analysis of patterns and events. The use of in-depth

semi-structured interviews was designed to allow for the emergence and analysis of the dynamic processes that are part of any caregiving history.

SAMPLE

The sample was drawn from the Ohio Longitudinal Study of Aging and Retirement (Atchley, 1981). All participants in a 1991 longitudinal study screening (N=468, age 66 to >90) who indicated that they had provided primary or secondary care to a parent or spouse in the last ten years were invited to participate in this study. This process yielded nine daughters, four sons, four wives and six husbands. The sample age range was 70 to 88; all caregivers but one, an African-American, were white; all were small-city dwellers; all were middle class. The sample included a mixed composition of primary and secondary caregivers; for that matter, many in the sample had provided both primary and secondary care to their care receiver along the caregiving path. Of the twenty-three caregivers represented in this study, eight were still providing care at the time of the interviews. The care receivers in all other cases had died.

DATA COLLECTION

The data collected for this study were the verbatim responses to semi-structured interviews. Two interviews were held with each participant. The first interview was loosely structured to allow the respondents to tell their stories in a way that allowed them to identify the meaningful elements of the caregiving experience. Second-round interviews were more structured, grounded in the analysis of the first round of interviews. Member-checking, the process of

seeking feedback from participants in a mutual and ongoing process of data analysis (Lincoln and Guba, 1985), was employed at the time of the second interview. Interviews were audio-taped for verbatim transcription.

DATA ANALYSIS

Data analysis in a qualitative project is theory-generating and on-going in nature. That is, analysis begins even in the first stages of data collection and is shaped in the member-checking process. The transcribed interview texts were the final data for analysis in this study. A coding process developed by Anselm Strauss (1987) facilitated developmental analysis beginning with an open coding system and the identification of concept indicators (e.g., "owed" indicates *debt* and "who else would have done it?" indicates *only one*) and moving to more focused coding as the analysis developed (e.g., *debt* and *only one* contribute to *impulse to care*). Core categories (e.g., *impulse to care* and *economy of reserves management*) were identified and integrated to construct a framework for understanding the dynamics of the caregiving experience over time.

Findings

The caregivers interviewed demonstrated a conscious pursuit of objectives related to the well-being of the self as well as the care receiver. In addition, the caregivers pursued objectives related to marital and filial relationships. Husbands and wives

consciously worked to preserve the fundamental nature of the marital relationship: the mutuality or reciprocity of care, the fulfillment of marital roles, respect for individual dignity, and in one caregiver's words, "a commitment to intimacy". Caregiving sons and daughters pursued a reframing, or sometimes, restoration, of the filial relationship, where mutuality or reciprocity of care is less normative than in the marital relationship, where roles become confused, and where a commitment to intimacy (physical, geographical, emotional) has not necessarily been sustained over the years.

The decline of the care receiver's physical and/or cognitive function, however erratic or incremental, is subjectively experienced by the caregiver as a slippery slope. Caregivers, who have been propelled onto the caregiving path by their own impulse to care, begin with a set of reserves, or a level of capacities for and commitment to caregiving, which is taxed in the caregiving process. Decline in care receiver function and caregiver reserves does not by itself determine the caregiving paths of spouses or sons and daughters. Instead, caregiving paths are conscious constructions: decisions and behaviors reflective of the tension between the slippery slope of care receiver physical/cognitive decline and the pursuit of objectives for the care receiver, the caregiver him/herself, and the marital or filial relationship. Caregiver decisions and behaviors over time represent an economy of *reserves management* employed to sustain caregiving activity and the pursuit of these objectives.

The impulse to care, a multiply-determined and not always conscious response to the dependency of a spouse or parent, sets caregiving activity in motion.

THE IMPULSE TO CARE

What is it that propels caregivers onto the path of caregiving? The impulse to care, a multiply-determined and not always conscious response to the dependency of a spouse or parent, sets caregiving activity in motion. Caregivers in the study attempted to grasp and define this impulse to care, made conscious by the interviewer's question "Why did/do you give care?" The variation in and complexity of responses demonstrate the idiosyncratic nature of the caregiving experience at the outset, and the problem of generalization. Most caregivers interviewed demonstrated the multiplicity of factors impelling caregiving by attributing their activity to *some combination* of the following: commitment to social standards of behavior and role fulfillment (doing "what one does"); an opportunity to express personal standards of behavior and role fulfillment; feelings of affection and love; "natural" responses to crises whether socialized or instinctive; being the "only one"; repayment of debt; a "selfish" need to keep the care receiver alive; a commitment to family precedent; and the intertwining of "having to" and "wanting to" give care. These combinations are demonstrated in the following quotes:

I feel very strongly when there's someone in need I want to help them.

And maybe that was all part of it, that he was a helpless, very, very, very sick man, and so totally helpless and needing care, but who else would have done it? (Wife)

* * *

I just assumed that this is what one does....You don't talk about am I a good person....No, you do what you have to do for somebody you love. (Husband)

* * *

It was just such a natural thing, I just don't think we ever thought about it in our conscious, or it being the right thing to do, or.... it was just a real easy, natural thing.... In our family, it just seems like it was what you do for somebody else, it's not to pay back.....It's just a natural thing. (Daughter)

* * *

I kind of think that is what my role in life is, to just be that person that can be there for you. And I want to be there for my mother. Whatever it is that she needs, I want to be that person who can say, Sure, Mom, I can do that for you. (Daughter)

* * *

You do it because it is a responsibility. My mother and dad had given me a lot and you just don't abandon someone. A mother and dad to me is a real important thing.....

Any burdens that I had were of my own choosing. I think duty is something that is self-imposed. (Son)

* * *

Although some caregivers earnestly attempted to explain the impulse to care in simple terms, its complexity was inevitably betrayed in the attempt, for example in the following quote:

I think, we did it simply because we loved her.. ...It was simply a matter of me being me.I mean, this is--- it's the same as what I would do for my daughter, or my grand-daughter, or for my son-in-law, for that matter.....It just seemed normal. I mean, this is what one does, isn't it? [It is] unexplainable. You just do what you somehow have to do, or want to do, or whatever the word is, I don't know. You just do it. I don't think for me anyway, they're separable terms. (Son)

It should be noted that much has been made in the literature of gender differences in the caregiving experience (Dwyer and Coward, 1992). Indeed, gender differences were evident in this study, and are identified where they are salient. The analysis in this study yielded important shared responses across gender, however, and it was the differences between *spousal and filial* caregiving that emerged as more significant. Therefore, the findings presented here are organized with spousal and filial distinctions, with only incidental gender distinctions.

Caregivers communicated the sometimes contradictory pursuit of the preservation of the physical, social, and emotional well-being of both the self and the care receiver over time.

THE PURSUIT OF OBJECTIVES

These caregivers communicated the sometimes contradictory pursuit of the preservation of the physical, social, and emotional well-being of both the self and the care receiver over time. In addition, both spousal and filial caregivers communicated a primary commitment to the marital relationship and the family of procreation (vs. the family of orientation). For spouses, this meant pursuing the preservation of the marital relationship in the caregiving experience. For sons and daughters, this meant accommodating the needs of the parent(s) while protecting the interests of the immediate family (of procreation); sometimes it also meant restoring or reframing the filial relationship.

The Well-Being of the Care Receiver

The motivation to provide for the physical, social and emotional well-being of the dependent parent or spouse is evident in the following quotes:

I wanted to try and keep him alive.
(Wife)

* * *

I loved her and hoped that she could recover....(Husband)

* * *

I felt I did the best I could under the circumstances, but I really felt bad that I couldn't make her happier. (Daughter)

* * *

The nursing home meant safe haven. I mean, whenever she needed something, there was somebody there to give her care. (Son)

* * *

I suppose I was always trying to be protective of his dignity. (Wife)

The Well-Being of the Caregiver

While pursuing the preservation of the care receiver's well-being, the caregivers also strive to protect their own physical, social, and emotional well-being in the face of an experience frequently characterized by stress and burden. Nearly all of the caregivers expressed this striving as a tension between their own needs and the needs of the care receiver:

[Sometimes] I just want to feel out from under. That's not very often, and what kicks in then is a little bit of a guilt trip. (Wife)

* * *

I feel guilty sometimes because I know how bored she must get, and I know how bored I would be if I were confined that way, but I do have a

life to live, too, and I have used judgement on that. (Husband)

* * *

[A nurse] said (about nursing home placement), "You have to understand, first of all what's best for [your wife]... and secondly, if you keep this up, you'll be dead in two years." And finally, I said I don't need to die...just because [my wife] is dying. (Husband)

* * *

I believe it was selfishness on my part. I am doing the best I can, you know, if I do anymore, it will be so much effort, and that is something I am not willing to go to at this point....What do I mean by selfish? Infringement on my rights. (Son)

* * *

(Regarding sharing residence with father): I consciously thought I can't give up my life.... (Daughter)

* * *

I'd be tired and I'd think, Oh Mama, you demand so much of my time, and I was just exhausted.... So I went to my doctor and he said, "Your mom is living your life. You are not living your life." He said, "You got to get away." (Daughter)

The Primacy of the Marital Family

All caregivers interviewed for this study, both filial and spousal, demonstrated a primary commitment to the marital relationship. For spousal caregivers, this meant making caregiving decisions that worked first to preserve elements characterizing their marital relationships, and then to accommodate other interests and needs. For filial caregivers, the primacy of the marital relationship and the family of procreation meant making caregiving decisions that first functioned to protect the family of procreation, and secondarily to meet the needs of the dependent parent or parents. Such an ordering of priorities was not without conflict for either caregiver type, however. As a matter of fact, for some filial caregivers, this choice-making (between the family of procreation and the family of orientation) was agonizing.

It should be acknowledged that elderly spousal caregivers face fewer role conflicts in their caregiving pursuits than do filial caregivers (Johnson and Catalano, 1983; Young and Kahana, 1989). For the vast majority of elderly spousal caregivers, the most active phase of parenting has passed, and spousal caregivers have the "luxury" of focusing on the marital relationship. In addition, most spousal caregivers have left the work force and the roles inherent in their jobs. In contrast, filial caregivers to elders are often engaged in simultaneous and sometimes conflictual caregiving, child-rearing, and career pursuits. It may be, then, that married filial caregivers focus on the marital relationship and the related child-rearing and bread-winning activities because they *have* to,

while spousal caregivers focus on the marital relationship because they are *able* to.

Spousal caregiving

It is important to consider the differential effects of the normative expectations for spousal caregiving and the lack of clear norms for filial caregiving. Many spousal caregivers referred to marital vows taken which made the preservation of elements in the relationship through caregiving contractual. This finding lends support to other research findings which suggest a congruency between the marital contract and caregiving expectations. (Fradkin and Liberti, 1987; Miller and Montgomery, 1990; Troll, Miller, and Atchley, 1979)

I think it is more kind of a mutual reciprocity that is part of our whole relationship. Always has been.... Part of particular marriage vows is the old "for better or worse, sickness and health, richer and poorer" business, which is supposed to apply mutually.... I guess being a wife in relation to caregiving suggests a commitment to intimacy of all kinds. And caregiving can be pretty intimate. (Wife)

* * *

It was just part of the relationship.... when she couldn't do it, I did it. (Husband)

* * *

My concept of marriage is these are responsibilities which you are voluntarily assuming when you take on that relationship. (Wife)

* * *

I just try not to break vows that I've made. (Husband)

For some spousal caregivers, simply sustaining the relationship by sustaining life was paramount.

He wanted to be home, and I wanted him to be home, no matter what condition he was in.... Why wouldn't I? I was selfish. I didn't want to give him up. I couldn't face losing him. (Wife)

* * *

I just felt, you know, I'm glad we were able to keep the thing going as long as we did.... That's just what you do---you keep a family together. (Wife)

Spousal caregivers discussed the importance of decisions that normalized the marital relationship and its particular characteristics.

Spousal caregivers discussed the importance of decisions that *normalized* the marital relationship and its particular characteristics. The following quotes are from a wife who hired all of the personal, nursing care done for her husband, which

freed her to proceed with a husband-wife relationship less altered by caregiving tasks.

I'd go in in the evening after they had him ready for bed and tell him goodnight and lean down and kiss him and put my arms around him or something....As always, he was quite independent, as independent as he could possibly be, and I always---I never went out of my way to be helpful for that reason, because he was quite proud of what he could do....

He's a very careful man, and very fastidious. And for me to have to change his Attends....He didn't like it and I didn't like it. We had a nice relationship....I would see that it was just gonna be ruined if I was gonna get into that....I don't know, it seems to me if you've wiped up after babies---but you hate to think that it's your husband....[Cleaning him] is practically impossible.

If I had been stuck with the physical care of him and had to lift him and dress him and bathe him and everything, I just didn't want to do that. When I think about it....it ruins the relationship. I'm sure it would.... if a woman had to do that for her husband.

In contrast to the thinking expressed above, one caregiver (a husband) reported the increased closeness that the very acts of intimate caregiving had brought to the marital relationship.

We're closer in many respects and she often says how much she trusts me, depends on me.... I suppose I give more than I ever have. She often says...how good I am to her and all that sort of thing, and she never, well, she never had occasion to before, I guess, but we never talked about those things. And she wants to hold my hand, which we never, hadn't done for many years. She clings more.

Spousal caregivers also presented caregiving as an extension of marital roles already in place. For wives, this role continuity often meant extending domestic duties to include more intimate forms of care.

Caregiving was part of a continued role I had with him, always providing for him, and his meals and so forth....I think taking care of him while he was ill was really a continuation of what I had been doing all along.

Some wives in the study suggested a process of borrowing from their experience as mothers in the caregiving process.

Aren't mothers caregivers?
(Daughter)

* * *

I suppose, when you've had children...you have a responsibility to children and I suppose I transferred that to [my husband].
(Wife)

More often than not, however, the wives struggled with having to make decisions for, or in some way have control over, their husbands, a significant deviation from their prior roles. Given the objective of preserving the nature of the marital relationship, this deviation meant serious discomfort.

Caregiving was a terrible burden and...our role was sort of reversed... so I was almost a mother image to him. This was probably the most difficult thing I had to do....it was a terrible time for me. And it just broke my heart.

* * *

Making decisions for him was terribly uncomfortable....I probably had more anguish over that than anything, because we had always made decisions together.

* * *

I think it is important, most important for both of us in different ways, it is important for him to feel that he is capable in most areas still, and that he has some control....

* * *

He probably resents because I am the one who has to tell him when he can't do something....I try to do my best and if there is any time when he can make a decision, let him make it.

* * *

He was helpless, couldn't take care of himself. But I didn't like to think of him as childish or childlike....I think he always clung to the idea that he didn't want to be ridiculous.... You don't want to rob a person like that of what little he has left.

The concerns about power-dependency conflicts in caregiving expressed by the caregiving wives in this study were absent in the interviews with caregiving husbands. This is consistent with the research findings of Miller (1987), who suggests that there may be more continuity between caregiving and the male role than the female role in that "the males' assumption of authority over their wives" is a "natural extension from their authoritative role in the family."

Preserving the essence of the marital relationship

The tension between the preservation of the care receiver, the self, and the marital relationship in the face of care receiver decline and the passage of time is most clearly and dramatically represented by one caregiving husband who provided several years of in-home care, and several years of nursing-home-based care for his wife who suffered from a serious and progressive form of dementia. A very devoted husband, by his own description, he attributes his devotion to the history of the marital relationship, the special qualities of his wife and her devotion to him throughout their marriage.

I had a wife who had been good to me, kind to me, supportive of me, and I think it's that particular

circumstance is all I can say....that's the way it was because it was [she]....I'm dealing with a particular person in a particular circumstance.

So central was the marital relationship to this husband's caregiving that when the essential qualities of the relationship were rendered unpreservable by losses in the wife's physical and cognitive capacities, this husband forfeited not the caregiving of his wife but the notion that theirs was fundamentally a marital relationship. Correspondingly, while continuing to provide loving and attentive care to his wife in her last years, spent in a nursing home, he entered into a companionship with a female friend, calling it "one of the critical factors in bringing me back to life".

The [marital] relationship came first: the friendship, the love, and then suddenly the friendship was gone and just duty remained. The relationship was so different, because when she ceased to be a friend and became a patient... This was somebody I just had to then care for. That was when I decided that I needed the companionship. It is a violation of a vow I took, yet I knew my wife had left me (cognitively) two years before.... I said to myself, I did what I could do and she left me; I did not leave her, nor would I have, and she may have left unwillingly. I kept saying, more than once, I made a bargain with her. It's that simple, and as long as the conditions (you know who I am and... can do what I ask) are there, it is not a matter to be discussed....I'm not somebody who breaks pledges easily.

Filial caregivers and the marital relationship

Married filial caregivers spoke frequently of the choice to defer to the needs of their spouses and children when confronting conflicting obligations: to the dependent parent and to the spouse and children. In very strong terms, some spoke of their caregiving activity as a disruption to their marital life and family, and had given clear priority to the marital family.

[Even if I had been able to lift her] I would not have brought my mother home, because I don't...I think you owe something to your own family, and that would have been a disruption. I do think you owe your own family something. I'd live in one room before I'd live with my parents. Because it just doesn't work, two families in one house. (Daughter)

* * *

There were thoughts about [bringing mother home] and if there were discussions they were over in a hurry, because I would not permit anything to interrupt my family. Having two generations under one roof is just an impossibility....You are running the risk of the destruction of your own home. (Son)

* * *

I was worn out in one sense of the word, but another sense is that it conflicted with family life. I put [my wife] under stress by being gone (to care for parents in their home). You can't go any place, and you can't do

anything because you're bound to her. (Son)

While most of the filial caregivers clearly reported the need to protect their own marital relationships as a factor in their caregiving decisions, the daughters in particular reported relying heavily on the support of their spouses and children as they pursued their caregiving activity.

If you don't have support [from your husband and children] I can see where it is terribly difficult for others. For me it was not difficult.... Everyone wanted her here. Yet, [as mother declined] I knew somewhere down the line, I'd probably have to face the fact that....I couldn't ask the family to keep on putting up with this. (Daughter)

* * *

[My husband] was awfully good. He really was. He never complained very much---very much?---he didn't com-plain at all, because he knew it was important to me. (Daughter)

* * *

It bothered me that it was not agreeable with my husband to have her live with us.... She really wanted me to ask her to come live with us, and I said, "I just can't, Mother, I've got a husband.".... I had to choose, even though it would be hurting my mother. (Daughter)

While spousal caregivers appear to be asking along the caregiving path, "How can I still be a husband (wife) to this woman (man)?" filial caregivers are not asking "How can I still be a child to this parent?"

Reframing the filial relationship

While spousal caregivers appear to be asking along the caregiving path, "How can I still be a husband (wife) to this woman (man)?" filial caregivers are not asking "How can I still be a child to this parent?" As a matter of fact, it has been a central task of the child's adult life to accommodate the changing nature and expectations of the parent-child relationship. Children facing the dependency of a parent have not necessarily achieved such an accommodation in a way that prepares them for a filial caregiving role. As stated earlier, in the filial relationship, mutuality or reciprocity of care is less normative than in the marital relationship, roles are confused, and a commitment to intimacy has not necessarily been sustained over the years. Finally, children's responsibility to parents has not been made explicit by vows of mutual obligation such as have occurred in the marital relationship. In the absence of clear norms for filial caregiving, sons and daughters confront a certain amount of role confusion. In this study, the daughters in particular expressed some discomfort with the new dynamics of the parent-child relationship.

It was almost like a reversal of roles, it's what it is. She was so dependent on

me. I think even more dependent on me than I was when I was a child. It's hard to tell your mom what to do, and yet you have to do it....It is hard because she is Mom, because she is the adult. (Daughter)

* * *

They were so dependent...they couldn't do anything without asking me.... you know, I was God. They just thought I was wonderful....I would have liked a little less dependency..... (Daughter)

Sons in the study appeared able to reconcile any role confusion by assuming roles of "responsible" sons and family members, in a "man-of-the-family" style, and were able to assume authority over their parents more comfortably than the caregiving daughters.

I was brought up to be a responsible person. It was just something that needed to be done, and I was there to do it....It's just part of your role of being a responsible member of the family. (Son)

* * *

There's just more of a sense of responsibility than anything else. [My past relationship with my mother] probably keeps my decisions more business-like. (Son)

* * *

I guess I feel the male is the person responsible for the family relation-

ships. The financial... seeing that everybody's OK. I think that's a male kind of feeling, versus the close tie, love relationships that I think are maybe more feminine. (Son)

CAREGIVING AS A SLIPPERY SLOPE

Caregiving is an activity represented by a variety of patterns of onset and progression. In some circumstances, the onset of caregiving is barely perceptible, taking place in subtle losses in care receiver function, with correspondingly subtle assumptions of caregiver responsibility. In other cases, the onset may be sudden and dramatic, such as in the event of a severe stroke or heart attack, when the lives and roles of the care receiver and the caregiver(s) are turned upside-down. Likewise, the subsequent progression of losses in function may be either negligible, incremental, episodic or precipitous. Therefore, several caregiving path scenarios are possible. For example, the care receiver may experience subtle and gradual losses over a long period of time from an imperceptible onset; the care receiver may experience a sudden and dramatic loss of function, but may remain stable at the consequent level of functioning over a long period of time; or, the care receiver may experience both sudden and dramatic onset and precipitous decline in function even from that point.

The caregiving path is subjectively perceived by the caregiver as a slippery slope, from two perspectives: loss of care receiver function and/or loss of caregiver "reserves" over the course of time.

It was a series of events....I just went with the flow....I didn't even think of anything else. (Wife)

* * *

You're caught up in circumstances that are really almost beyond your control. You're faced with decisions that... have to be made right now. You don't even stop to think. (Wife)

* * *

Things went downhill real fast...I knew pretty early on that this wasn't ever gonna get better. Just gonna get worse. I guess I was just goin' along one day at a time, one foot in front of the other.... (Wife)

* * *

It was just downhill from there on. (Daughter)

* * *

Those things just built up....The situation gradually developed and I've done little by little and more and more.... (Husband)

* * *

It's like being on a treadmill---just keeps going faster and faster until finally you aren't sleeping, you aren't eating...you're just...you're doing it. (Husband)

Caregiver Reserves

Set on the course of caregiving by their multiply-determined impulse to care, and pursuing objectives for self, care receiver, and the filial or spousal relationship, the caregivers are endowed with a set of reserves employed to tackle the demands of caregiving. These reserves may be divided into three categories: the strength of the impulse to care; assets; and support.

The strength of impulse to care includes such elements as the level of devotion, affection, or love; the strength of sense of duty; the amount of debt perceived; the strength of need fulfilled by caregiving; the level of accountability felt toward vows or promises made; or the level of resolve to avoid nursing home placement.

Assets include such elements as financial resources, time, physical space or arrangements (including not only household environment but also proximity to goods or services), and the caregiver assets of physical health and strength, mental health (including emotional and cognitive functioning), knowledge, skill, and experience.

Support includes informal systems of instrumental and moral support (family, friends, and neighbors); the sometimes makeshift, quasiformal system of help somewhere between informal and formal assistance; and formal systems of care and support, including home-based and institutional services and professional services (doctors, social workers), as well as formal support groups. Spiritual reserves, acknowledged by two of the caregivers, are the faith and belief systems that serve as

sources of inspiration and guidance, and may be considered another kind of support.

Some elements of the reserves identified above are absolute and indispensable for caregiving activity, such as the asset of caregiver physical health and strength, cognitive function, or the asset of time, while other reserves, when absent or limited (e.g. supplementary supports, affection, access to goods or services) may be more easily compensated for by spending or exploiting other reserves. Still other reserves---knowledge and experience for example---may be gained in the very process of caregiving, at little direct cost to other reserves.

The caregiving path is characterized by a process of work toward building, sustaining, and protecting the set of reserves while they are spent, borrowed, traded, and saved.

Economy of Reserves Management

An economy of reserves management becomes a major dynamic of the caregiving path. The path is characterized by a process of work toward building, sustaining, and protecting the set of reserves while they are spent, borrowed, traded, and saved. Clearly, caregivers who enter the caregiving path with ample reserves are in a better position to pursue the objectives of caregiving (for self, caregiver, and relationship) in the face of care receiver decline and the passage of time. The threat to the realization of those objectives, represented by slippery slope of care receiver decline in function, is

moderated by the capacity of caregivers to exploit and spend reserves. The steeper the decline, however, the more reserves have to be spent and the less able the caregiver to achieve objectives. Even when the level of care receiver function is relatively unchanged, over a long period of time caregiver reserves may be depleted; this process of depletion represents another slippery slope. When the decline of the caregiver is both steep and long-lasting, the caregiver's objectives are especially at risk. Finally, reserves serve different functions at various times corresponding to the needs of the care receiver and the demands of the caregiving conditions.

Caregivers in this study demonstrated a creative and determined process of reserves management, as well as a certain level of awe or wonder at their own capacities for care.

There's a lot of things you do that you don't think you could. (Wife)

* * *

I suppose there is a limit somewhere. I didn't run up against it. (Daughter)

Strength of impulse to care

Not unlike the daughters in the study upon which this research was based, all of the caregivers in this study responded to the dependency of the care receiver with multiply-determined motivations and commitment to caregiving, which together may be described as the impulse to care. The assumption of caregiving responsibilities cannot be said to be impelled by any one factor in each case, and certainly no factor is

identifiable as *the* impelling factor across cases. For some, the sense of debt or duty was explicit and strong. For others, ideas of debt or duty only minimally contributed to their impulse to care; other factors, such as devotion or what was described as a simple "wanting" to give care were less value-laden but clearly at play.

Furthermore, these caregivers represented varying levels of strength of their impulses to care. Whatever the nature of their impulse to care, that impulse not only propelled the caregivers onto the caregiving path but functioned to sustain them, up to a point, in the face of the serious depletion of other reserves.

The following quotes represent the variety of sources of impulse to care:

It was just my devotion to him, really, was the basis for it all. (Wife)

* * *

I kept saying, I'm repaying a debt---but for *her*, I keep stressing---not just for anybody, you know. I'm not a saint...just was repaying a debt. If I had been married to somebody disloyal or uncaring....I would have felt no great sense of loyalty. (Husband)

* * *

My mother, especially, did so much for me and my family, even my husband and me, and I just felt I wanted to do it for her. I felt I owed it to her. She was always so kind and generous. (Daughter)

* * *

...I think that I'm a very religious person or my faith means a great deal to me, and we're being taught constantly to live for others. (Wife)

* * *

I've always been pretty strong on duty..... And I have always felt it was the duty of children to look after their parents. (Daughter)

* * *

In the background you're thinking, If I do not treat my mother right, will I be punished here on earth or in the hereafter? If I treat her well, will I be rewarded? (Son)

* * *

I just couldn't let [mother] go into a nursing home until we were sure that she had no idea of where she was or anything. (Daughter)

It is possible that the strength of the impulse to care may be depleted, like other reserves, and the momentum slowed, with the passage of time and/or the decline in care receiver function; however, for all of the caregivers in this study, the impulse to care outlasted other reserves.

If the impulse to care functions to propel caregivers onto the caregiving path, the strength of propulsion appears related to the strength of the impulse, and the momentum produced by that strength functions as a reserve and a point of reference with which to explain or rationalize decisions to provide or sustain caregiving. It is possible that the strength of the impulse to care may be depleted, like other reserves, and the momentum slowed, with the passage of time and/or the decline in care receiver function; however, for all of the caregivers in this study, the impulse to care outlasted other reserves. The major caregiving shifts (after assuming care), sharing and relinquishing care, were consequences of either the depletion of other reserves, the decline in care receiver function, or both. Caregiving shifts were a result not of a loss of *will* but a loss of *way*.

Given the sometimes conflicting objectives of preservation of the self, the care receiver, and the marital or filial relationship, it is not surprising that the management of these reserves was often experienced as conflictual.

Assets

The caregivers in this study were endowed with a range and variety of caregiving assets which enabled and sustained their activity along the caregiving path. These assets are in most cases more tangible than the impulse to care, and are more explicitly identified as factors in

caregiving decisions. Propelled and sustained by personal convictions, beliefs, and motivations that form the impulse to care, the caregivers in this study sought to manage the more tangible reserves in the pursuit of their objectives. Given the sometimes conflicting objectives of preservation of the self, the care receiver, and the marital or filial relationship, it is not surprising that the management of these reserves was often experienced as conflictual. For example, for many caregivers, the reserve of time required supplementation achievable only by foregoing employment; for many caregivers, foregoing employment meant an intolerable loss of financial reserves necessary for the preservation of the self, the care receiver, and even the marital relationship. It is evident that foregoing employment or other activities for the sake of time may represent for some a loss in mental health reserves. For others, choosing to provide care directly, rather than using financial reserves to purchase care, may mean the depletion of physical health reserves. For still others, purchasing care means the restoration of mental health reserves, or the capacity to maintain employment, and therefore the capacity to continue the purchase of services, etc. Such is the complexity and interactivity of reserves management on the caregiving path.

Time

The following quotes illustrate the issue of time management:

Everything else came to a screeching halt. All my obligations with anything I had been doing. (Wife)

* * *

When we found out about the Parkinson's, I looked at my life at that point to see what I could simplify and eliminate. I have tried to simplify so that I didn't have too many responsibilities to take me away.... (Wife)

I was working all those years, and that took 40-50 hours out of my week and there wasn't a lot of slack. (Daughter)

* * *

I juggled it....I had to work and have my income so I couldn't be with her twenty-four hours a day, and there was no one else, so, what's to do? (Daughter)

Adding work or other activities can serve as a "buffering effect" (Spitze and Logan, 1990). Though representing a loss of time for caregiving, the tradeoff is one of enhanced mental health reserves so important to sustaining caregiving activity.

My middle son came along and urged me to apply to be a docent, so I did that and I was out with some really nice ladies...[before that] I thought, there's no fun left in your life, that's for sure. (Wife)

Finances

Horowitz (1985) reports that emotional rather than financial issues contribute to strain in the caregiving experience, but the difference in available financial reserves at the onset of caregiving clearly manifests itself in different reserves

management decisions. Major caregiving decisions, such as nursing home placement or the purchase of in-home formal services, are clearly influenced by the level of financial reserves available to the caregiver and care receiver.

I know that we couldn't have afforded to give her care, you know, around the clock. (Daughter)

* * *

(Re: nursing home placement) Well, for one thing, I can just see the money. It would just go so fast, and where would we be? We would be just like all the rest of them, destitute, and have to go on Medicaid and everything else. It is scary. (Wife)

* * *

The nursing home represented quite a financial outlay. But I was determined to get the best in-home care we could afford. (Wife)

* * *

A nursing home would cost a lot of money and we don't have it...I think a nursing home would probably give her better medical care than I can.... From what I've heard, our funds would be exhausted in a year or two. (Husband)

Space and geography

For most caregivers, living arrangement and living proximity to the care

receiver was experienced as an asset or liability.

I kind of live with what I'm able to do. I'm too far away to do more. (Daughter)

One daughter made a conscious decision in the earliest stages of her parents' dependency to preserve the asset of geographic proximity at the cost of other life choices:

By the time I divorced, I thought about rearranging my life and going somewhere else, but by that time, I could see that they were not doing too well, and it was only going to get worse, and I decided with them being old and ill, it was not for me to depart for other places....I think leaving would have been pulling the rug out from under them. (Daughter)

Personal assets

A number of personal assets are drawn upon in the course of caregiving, including physical and mental health, knowledge, skills, and experience.

Physical health reserves. Although caregiving was invariably identified by these caregivers as physically draining, they demonstrated a willingness to tap their physical reserves to the point of exhaustion.

I got so I was losing weight, it was such an effort, and I said to Dad, you know, I don't think I'm going to be able to go on this way. (Daughter)

* * *

I was so exhausted most of the time....I had a terrible time with my back, and I was never without pain....I was really in great anguish over being on my feet a lot, very rarely getting any relief from waiting on him.... The first month was an absolute nightmare.... (Wife)

* * *

She was incontinent by then, and it was just out of control and out of hand, and I could handle the physical parts of it, but I couldn't handle something 24 hours a day. (Husband)

* * *

[W]e were completely worn out. (Son)

* * *

[I]t was too much for us to handle.... Dad was a big man. And we had to put Depends on him, and it took two of us to really take him to the bathroom. When they're dead weight, they're hard to handle. (Son)

Mental health reserves. Most of the caregivers reported struggling to maintain their own mental health while enduring the stresses of caregiving activity.

When I go to the grocery store once a week for an hour and a half or so, well that's about all that I get away from the house. Reading is my great consolation....As long as I have plenty of books, I can hold out. (Husband)

* * *

The stress was just incredible. (Wife)

* * *

You see, they (nursing home staff) change every eight hours....and I thought to myself at different times, I can't be fresh. I couldn't be fresh for my mom....and I was going to be so unhappy in this role that I would be unhappy and burdened. (Daughter)

* * *

It worked both ways, you know, the stress of not doing it when I should have or doing it when I didn't want to....Sometimes it didn't matter what I did---it was going to be wrong. (Son)

Knowledge. The caregiving experience requires knowledge about the illness or impairment of the care receiver and about the health care and service system available to the caregiver as well as the care receiver. For some caregivers, their knowledge or access to knowledge was a clear asset as they confronted the demands of caregiving.

My wife, God bless her, she being...knowledgeable about these things, had already researched places to take her. (Son)

* * *

There is a relief in knowing this [disease] has a name; there is something I can do about it. I may not be able to cure it, but at least

there is a pattern of procedures we can follow. (Wife)

Other caregivers related a knowledge deficiency which clearly affected their caregiving choices, often resulting in a failure to identify and exploit available help, for example. The cost of this failure was often the threat to other reserves, such as financial, physical, or mental health reserves.

Most of the time I didn't know the right questions to ask. (Husband)

* * *

I knew there was such a thing as home care services, but I didn't know it applied to me. (Wife)

* * *

It never occurred to me to apply to them (non-profit home health care agency). I just figured it was more of a charitable situation. And I really didn't need---people needed it worse than I did. (Wife)

* * *

I haven't really researched the nursing home problem, but some things I read and hear, and just incidental information, and I asked several people, but nobody seems to know any more about it than I do, so I haven't delved into it. (Husband)

Skills and experience. Just as caregivers in the study presented a range and variety of caregiving knowledge, they also presented a range and variety of caregiving skills and

experience that functioned as significant caregiving reserve assets or deficits.

I was glad I was able to manage financial affairs and do things about the house that needed to be done. I had always participated in that kind of thing....I knew how to handle things like that---pay the taxes and all. (Wife)

* * *

I'm not cut out to be a nurse.... [T]he physical contacts of the bedpan and all that are offensive to me even after months of experience...It's a very confining kind of job. (Husband)

* * *

The household management degraded a good deal on cleaning and planning things around the house. (Husband)

* * *

When I go to give someone an injection with a needle, that really upsets me. (Husband)

Support

Critical to the capacity to meet caregiving objectives in all cases in this study was the third form of reserves: support. Support may be either instrumental, material, or moral, and its sources are divided into three areas: informal, quasiformal, and formal support. Support may come in the form of direct care to the care receiver or moral or material support for the caregiver. Informal support is that support most often

provided by other family members but may include friends and neighbors as well. Quasiformal support is contracted care obtained outside of professional channels and organizations. Formal support is provided through a professional agency or organization. Whatever their form, the sources of support act as a set of reserves critical to the sustenance of caregiving activity.

Informal support

The following quotes reflect the commonly experienced benefits of caregivers receiving support from family, friends, and neighbors. Sometimes the informal support is substantial, such as the sharing of care among siblings, or with children. In other cases, informal support may be less substantial but no less significant, such as the moral support and advising so important to caregivers along the caregiving path.

[My] older daughter... took me aside and said, "You've got to do something to take care of yourself. You've got to get some time. You've got to get out. You've just got to do something." (Husband)

* * *

I think hospitals made suggestions (and two physicians) (and wife's two best friends). I would say those four people....were the people who gave worthwhile advice and I trusted explicitly all four of them. (Husband)

* * *

He needed 24-hour care, and the three brothers, all three of them lived here in town and we took turns. (Son)

* * *

[My daughter] was living at home and going to college. I think we both just sort of fit it in and did whatever we thought was needed at the time. (Husband)

* * *

I have nothing but respect, admiration, gratitude, for my daughters because of their concern for me....I would guess that two things saved my life. One was my daughters. (The other was female companion.) (Husband)

* * *

...I have friends and neighbors that are just marvelous. My next door neighbors were in and out every day and offering help and companionship... I had a list of at least a half dozen men friends who were always willing to come.....All of these friends just appear out of the woodwork. (Wife)

* * *

If I were gone, no matter how sick she would be, if I had to be away, [my husband] was perfectly happy to take care of her and well, [he] was just wonderful. (Daughter)

Some caregivers in the study described the limits of informal support available to them.

There are times when I think I wish they (siblings) would help me with the load. There have been times when I think, you know, at least pay attention to Mom. If they don't want to do anything about helping her, at least, pay attention to her. (Daughter)

* * *

Our friends were good but it was hard on them to come. I understood that it was hard on them. (Wife)

Spiritual support

The spiritual sustenance realized through religious faith served as a reserve along the caregiving path for these caregivers:

I wonder how I did it, but I know how I did it. The Lord helped me. I had some verses from Isaiah taped to the dashboard that I would read. I prayed the whole time. Oh, I prayed all the time. (Wife)

* * *

I ask God to please make me patient....When things happen to you, you wonder how you are going to get through this. If you don't have God, you can't get through it. You cannot do these things on your own. (Daughter)

Without the knowledge or understanding of how formal agencies and organizations might be of use to them, the caregivers took it upon themselves to marshal the necessary forces seemingly out of thin air...

Quasiformal support

Many of the caregivers in this study related a remarkable process of improvising supportive services. Without the knowledge or understanding of how formal agencies and organizations might be of use to them, the caregivers took it upon themselves to marshal the necessary forces seemingly out of thin air, locating quasiprofessional caregivers by word of mouth, or by running or posting ads, etc. The results were not always satisfactory.

One of these caretaking women that looked after my mother, one of the five, we had suspected that she had been stealing.... Imagine just trying to keep five women and their paychecks and all that straightened aroundWe realized, hey, he can't handle this with all these women and they were giving mother all the wrong kinds of food and she was gaining weight that she shouldn't have been gaining. (Daughter)

* * *

I had a stream of them....Only one time did I have help that I had to fire. She was just so crude. And she wasn't clean. She didn't like doing the work. It was a disaster. (Wife)

* * *

My mother became quite ill, I would say mentally and physically. She wasn't eating right. We got temporary help, sleep-in help, and that was a disaster through two or three different ones...and finally we just got tired of it, and convinced mother that we needed to make a change. (Son)

* * *

The hospital...gave me a list and I had to call and interview them, and you know, this was an added burden to me. Those arrangements for taking care of him...that was not an easy transition for me. (Wife)

* * *

[H]elp is so uncertain....[M]aybe they'd be there a while and then they're gone. Either that or....they steal you blind. (Daughter)

* * *

[T]he ladies who were caring for her were sort of a rip-off if you get down to it. (Son)

* * *

I just said, I'm going to get people to come in and stay with her for blocks at a time so I can just get away....I was so housebound that I was uncertain of my driving. (Husband)

* * *

I had one person that was not too professional....And then I realized that she was patronizing him terribly and acting...calling him endearing terms..."Honey"...and patting him and talking to him like a little boy....I got rid of her as soon as I could find someone else. (Wife)

Formal services

Although the use of formal services was for the most part more satisfactory than the catch-as-catch-can approach to improvising services, even formal services represented a mixed bag of support.

A girl came from social services once a month or once every two weeks, I forget how often, that did her blood pressure and all that....She was the sweetest thing, and she could tell you anything you wanted to know. (Daughter)

* * *

The hospital was very good about trying to help....and then we advertised....[W]e had [home health agency], and we had [an informal caregiver]. But other than that we were doing it ourselves. (Daughter)

* * *

I think that I did myself a disservice by not taking advantage of the Hospice counseling system...but almost all of their sessions were evening times, and I don't do much driving at night. I did seek some advice and counsel from [my minister]. (Wife)

* * *

[My wife] applied for home care or whatever you call it, and they would always have some reason why they couldn't pay....We could have used home care. (Son)

* * *

[I] couldn't find any [formal services] (1980-1986). When we checked it out we had such negative response, like I don't know where to look for these kinds of services, that I didn't bother to look anymore and I depended upon the informal. (Husband)

* * *

I had people who would stop in and check on them and then Meals-on-Wheels.....That was a great relief for me because I knew that they'd have something to eat. (Daughter)

Caregiver resistance to use of formal services. Especially remarkable in this group of caregivers was a level of ignorance or misunderstanding about the existence of formal systems of support and/or their eligibility for such support. Although support generated by doctors or hospital staff (e.g. discharge planners) was generally well-

received, support available through social service agencies was often associated with "charity" and not considered relevant to the family circumstances. On the other hand, for-profit services were considered with suspicion by some.

You have to take the help that they send around...and it might not have been so great. (Wife)

* * *

That's (for profit home-care services) a racket, it really is. (Wife)

* * *

The family home service has offered [respite care] but they always say, well they would like a week or so notice, and I don't see myself going out and sitting in the park for an hour or so.... (Husband)

* * *

I have to say that being [the only child] I did what I thought was best, but I had no choice (other than nursing home placement). And I'm not sure I would have relinquished any of those responsibilities to somebody else, either.....[T]hey don't do it right, then they got me on their back. I don't want any problems. (Son)

Care receiver resistance to the use of formal services. Even when services might have been available, accessible, and satisfactory, they were not always welcome by the care recipient.

I even investigated Meals-on-Wheels for her....I contacted those people and got it all set up when she said, I don't think I want it. (Daughter)

* * *

(Re in-home care) [S]he was very, very particular....there was just never any one who suited. And it's so expensive. It's more so than a nursing home, and that's plenty expensive. (Daughter)

* * *

One thing that I am not sure about is how he would feel if he got to the point where I couldn't manage all of the care and had to have somebody else coming in the home. I don't know how he would handle that because he is such a private person, I think it would be pretty difficult for him. I think it is often more difficult for a man than for a woman. (Wife)

* * *

We tried to get her something like Meals-on-Wheels.... [T]he people went to my mother and she wouldn't let them in the house. (Son)

The nursing home. Clearly, nursing home care represents the most radical choice of formal support. One wife commented, "I guess it's sort of like knowing where the life preserver is on the boat, but hoping you won't have to use it." For others, however, using that life preserver became a necessary choice, and primary care was relinquished to the nursing home.

Having her in the nursing home is such a burden off of me. I had all the care before: Is she taking her medicine right? Is she eating right? What does she need from the store? Find her bills so we can pay them. Do this. Do that. Just constant stuff. (Daughter)

* * *

I couldn't restrain her. She wouldn't let me. I can't handle that, but professionals can handle it. (Husband)

* * *

I said, when she would like to have been home, Mother, you would have to find three people, and it's hard to find people. You have to have round-the-clock care. And I couldn't be there all the time. (Daughter)

* * *

The nursing home takes a lot off your mind, you know, when you don't have to worry about help yourself. It gave you peace of mind. (Daughter)

* * *

I didn't really feel I could handle her at that point....Because it took several nurses to move her and all. We just didn't consider bringing her home. (Daughter)

Use of support groups. At least one caregiver found that the use of a formal support group composed of both caregivers and care receivers functioned to sustain her and her husband.

Right from the very beginning he was willing to go to the support group which astounded me because I could never get him to even think about any kind of support group or anything of that kind..... I have felt there's some real supportive interaction going in the group. (Wife)

Two men in the study spoke particularly of their resistance to participating in groups for support.

I wouldn't [attend a support group] because I thought I understood what had to be done and I didn't want to go and listen to other people talk about this. If I could be helpful to somebody, I didn't mind doing that, but I didn't want somebody telling me....I didn't want to go to a group where people are just unburdening themselves, and one of these consciousness-raising type things....I understood people had problems, but.... (Husband)

* * *

I'm not much of a joiner...I've never attended any functions at the Senior Center, and never felt any need to...I'm not much of a group person. (Husband)

Conclusions and Policy Implications

That caregiving is a complex and dynamic process has been understood in the past decade of very active study of caregivers' experiences. Through their stories, the caregivers in this study have contributed to our understanding of their impulse to care, the objectives pursued on the caregiving path, and the important process of reserves management undertaken to sustain caregiving activity toward the achievement of those objectives.

This increased understanding in turn contributes to the identification of several implications for long-term-care policy. We know from this study that the impulse to care, as conceptualized in the earlier study of caregiving daughters, is not a phenomenon exclusive to daughters. The impulse to care is a multiply-determined response to the dependency of a family member requiring long-term care. Interviews with caregiving daughters, sons, husbands and wives, affirmed the presence of the impulse to care in all caregiver types. Furthermore, the interviews revealed the many forms that factors contributing to the impulse to care may take: commitment to role fulfillment, feelings of affection, devotion, duty, debt, etc., socialized or instinctive responses, all expressed from a framework of the parent-child or spousal relationship. Interviews with these caregivers did not contribute to a typology of impulses by caregiver type;

rather, the interviews illustrated the variability within caregiver types, and the idiosyncratic nature of the impulse to care in spousal and filial caregivers of both genders.

What we can know about the impulse to care is that it is exploitable.

What we can know about the impulse to care is that it is exploitable; with three out of four in-home frail elders receiving care from family members, it is both difficult and not difficult to understand why policymakers regard the family as an "untapped resource" Horowitz (1985, p. 200). Caregivers in this study demonstrated a remarkable capacity to satisfy their impulse to care and to meet caregiving objectives through the management and expenditure of individual reserves over time. When support services were absent, inaccessible, or perceived to be irrelevant to the caregivers' or care receivers' circumstances, caregivers simply proceeded without the support, spending other reserves instead.

While individual caregivers are utilizing their own economies of reserves management, policymakers have employed a long-term-care economy of their own, with family members serving as the greatest reserve for caregiving. The institutional bias of long-term care policy and the related reluctance of policymakers to spend financial reserves on family caregiving support suggests an injudicious economy with serious implications. Caregivers in this study have demonstrated a strong resistance to nursing home placement when other supports are

available and accessible, and when they are compatible with caregiving objectives. However, as reserves are spent on the slippery slope of caregiving, the depletion of reserves creates a threshold of support beyond which caregiving cannot be sustained. Institutional care is the outcome of such a process.

An effective public economy of long-term care reserves management would provide services that 1) recognize the exploitability of the impulse to care; 2) are sensitive to caregiving objectives, particularly as they relate to the preservation of the marital relationship and the need to comfortably reframe the filial relationship; and 3) that assist with the management of all caregiving reserves. Implementation of the following recommendations would contribute to an enhanced compatibility between individual and public economies of caregiving:

1) Of particular concern are the problems evident in the unsatisfactory, even disastrous, experiences of caregivers improvising a "system" of quasiformal support. Caregivers improvised such support when they believed other services were not available, accessible, or relevant to them. Operating from the assumption that their control of personnel was greater when customizing their own support system, the caregivers were in most cases faced with unreliable, unprofessional, or inappropriate care. Services directed at some quality control would, at the very least, provide a registry, clearinghouse, or referral service when quasiformal care is sought.

2) Even when formal support service systems are available they appear in some

cases to be either underutilized or unsatisfactory. Effective public education and outreach should be undertaken to enhance access, clarify eligibility, and reduce the stigma associated with public services and the distrust of for-profit services.

3) Service systems should provide for increased caregiver and care receiver choice of personnel and services sought by both caregivers and care receivers.

4) Agencies and organizations should institute services directed at strengthening the caregiver reserves of knowledge and skills by training family caregivers for specific caregiving tasks.

5) Service organization philosophy should be founded on an appreciation for the objectives of caregiving as they relate to the spousal or filial relationship; service delivery programs should be designed to enhance, not impede or supersede, those relationships.

6) Mental health services should be expanded and specified to serve the emotional needs of caregivers and care receivers.

7) Financial supports for in-home care should be expanded to compensate for the loss of family reserves, preventing premature institutionalization at greater public and personal cost.

The stories of the twenty-three caregivers interviewed for this study enhance our understanding of how characteristics, behaviors, attitudes, and conditions interact on the path of caregiving over time. Although the reader is cautioned against gross generalization, careful application of these findings should contribute to more

informed, sensitive and effective social policy in long-term care. Family members are indeed a resource, when tapped appropriately and supportively, for a caregiving experience that satisfies the objectives of both the caregiver and the care receiver under even the most challenging conditions.

Bibliography

- (1995) Atchley, R. C. *Description of the Ohio Longitudinal Study*, Scripps Gerontology Center, Miami University, Oxford, Ohio.
- (1990) Brody, E. *Women in the Middle: Their Parent Care Years*. New York: Springer Publishing Company.
- (1992) Dwyer, J. W. and Coward, R. T. *Gender, Families, and Elder Care*. Newbury Park: Sage Publications.
- (1987) Fradkin, L. and Liberti, M. Caregiving. In P. B. Doress and D. L. Siegal, eds. *Ourselves Growing Older*. (pp.198-212) New York: Simon and Schuster.
- (1985) Horowitz, A. Family caregiving to the frail elderly. In Eisdorfer, *et al*, eds. *Annual Review of Gerontology and Geriatrics*, Vol 5. New York: Springer, 194-246.
- (1983) Johnson, C. L. and Catalano, D. J. A longitudinal study of family supports to impaired elderly. *The Gerontologist*, 23, 613-618.
- (1985) Lincoln, Y. and Guba, E. *Naturalistic Inquiry*. Beverly Hills, CA: Sage Publications.
- (1991) McGrew, K. *Daughters' Decision Making about the Nature and Level of Their Participation in the Long-Term Care of Their Dependent Elderly Mothers: A Qualitative Study*, Scripps Gerontology Center, Miami University, Oxford, Ohio.
- (1990) Miller, B. Gender differences in spouse management of the caregiver role, in *Circles of Care: Work and Identity in Women's Lives*, E. K. Abel and M. K. Nelson, eds. Albany: State University of New York Press.
- (1990) Miller, B. and Montgomery, A. Family caregivers and limitations in social activities. *Research on Aging*, 12, 72-93.
- (1990) Spitze, G. and Logan, J. More evidence on women (and men) in the middle. *Research on Aging*, 12, 182-198.
- (1987) Strauss, A. *Qualitative Analysis for Social Scientists*. Cambridge: Cambridge University Press.
- (1979) Troll, L. E., Miller, S., and Atchley R. *Families in Later Life*. Belmont, CA: Wadsworth.
- (1989) Young, R. and Kahana, E. Specifying caregiver outcomes: Gender and relationship aspects of caregiving strain. *The Gerontologist*, 29, 660-666.