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Source: *Journal of Marriage and Family*, Vol. 50, No. 1 (Feb., 1988), pp. 197-207

Published by: National Council on Family Relations

Stable URL: <http://www.jstor.org/stable/352439>

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## Family Responsibility and Caregiving in the Qualitative Analysis of the Alzheimer's Disease Experience

*Following the trend of research on the caregiving side of the Alzheimer's disease experience, field data are presented in illustration of the interpretive dynamics of family responsibility. Four features are addressed: social comparison, issue contingency, family history, and kinship priority. It is argued that qualitative analysis offers empirical lessons about family responsibility and caregiver functioning that remain untaught by other methods.*

Research on the caregivers of Alzheimer's disease (senile dementia) patients has come a long way in a short time. In work coinciding with the rapid growth of the Alzheimer's disease movement, centered in the Alzheimer's Disease and Related Disorders Association (ADRDA) and its emphasis on self-help and family support, researchers have examined, over a ten-year period, how the patient's impairment affects caregiver functioning and the risk of patient institutionalization. Reflecting the trend of research in general, Gwyther and George (1986) summarize the contributions of papers from a recent symposium as (a) showing the relative unimportance of the impairment for understanding caregiver functioning and (b) drawing attention to the heterogeneity of family caregivers.

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As far as impairment and caregiver functioning are concerned, researchers have documented the complexity of the relationship. While they continue to test hypotheses about the variables' interrelationship (Deimling and Bass, 1986; Deimling and Poulshock, 1985; Morycz, 1985; Poulshock and Deimling, 1984; Zarit, Reever, and Bach-Peterson, 1980; Zarit, Todd, and Zarit, 1986), their findings indicate that the felt burden of caregiving has a logic separate from the degree of impairment. For example, Zarit and associates (1980) found that the caregiver's felt burden was lessened by relatives visiting the dementia patient's household. Poulshock and Deimling (1984) note that studies need to consider not only the impact of the objective impairment on the caregiver but caregivers' subjective interpretations of impairment. Poulshock and Deimling (1984) and Deimling and Bass (1986) point out that impairment should be discerned in terms of the different ways it affects caregivers, distinguishing, say, disruptive behaviors from cognitive deficits.

Concerning the heterogeneity of family caregivers, researchers are increasingly cautious not to homogenize caregivers in the overall care equation. While some have studied the impact of dementia on the family (Deimling and Poulshock, 1985; Seelbach and Sauer, 1977; Treas, 1977; Zarit et al., 1980), others have indicated the importance of disaggregating family members. Brody (1981), for one, reminds us that families do not just continue to help their demented elders as

a whole, as Shanas (1979a, 1979b) has so forcefully documented, but that certain family members—especially those Brody calls “women in the middle”—experience caregiving differently from others. Johnson and Catalano (1981, 1983) have further described the family caregiver by taking family status into account in evaluating elders’ support systems. They reported that impairment affects a childless married elder differently than a childless unmarried one. The adaptation of the childless married leads to withdrawal from external social ties and greater spousal involvement; the childless unmarried adapt by means of long-term, extended family and friendship linkages. Johnson and Catalano also have alerted us to the different kinds of adaptive strategies used to adjust to the burdens of care: children are likely to engage in “distancing,” while spouses find themselves progressively “enmeshed” in the caregiving relationship.

Following the trend of research, this article considers how kindred enter into caregivers’ ongoing sense of responsibility in caring for an Alzheimer’s patient at home. It is argued that while the complexities of family relations affect the sense of responsibility, they are not static factors operating to determine caregiver functioning. Rather, the interpretive dynamics of caregivers’ concern with the family side of responsibility serves continually to articulate the understanding of caregiver functioning. The article presents data to illustrate how the interpretation of familial factors shapes the meaning of responsibility in caregiving.

#### APPROACH AND METHOD

In an anthropological study of the coping strategies of older people, Wentowski (1981) reversed the way gerontological researchers usually approach the relationship between social support and kinship bonds. Instead of comparing family and nonfamily networks for their patterns of support for elders, Wentowski asked how systems of supportive exchange affect definitions of kinship. She found, for example, that nonkin helpers may assume responsibilities often assigned to kin when the latter are unavailable, and that a good share of the nonkin helpers and those helped secure their relationship as close friends by becoming fictive kin. An elder who feels her neighbor to be “really more like a daughter”

engages the respective roles’ rights and obligations. Regarding the usual approach, Sokolovsky and Cohen (1978) have pointed out that the specification of the part played by support networks in older persons’ functioning (e.g., Brody, Poulshock, and Maschiocchi, 1978; Lopata, 1975) does little to inform us of how social relationships are interpreted and used.

The study reported here kept usage at the forefront of the analysis of family responsibility and caregiving, emphasizing the interpretive activity and circumstantial conditions that bore on definitions of their relationship (cf. Gubrium, 1988). As Sokolovsky and Cohen suggest, usage tells us more about what people do with so-called family factors than about how the factors affect or determine people’s actions. The aim of the study was to make usage visible as a display of the dynamics of interpretation. In this presentation of the data, the persons concerned are shown in the process of *assigning* meaning to the relationship between family responsibility and caregiving.

The method follows from the approach. Participant observation and focused interviewing provided the means of capturing the dynamics under consideration. As part of a continuing study of the social organization of senility (Gubrium, 1986), support groups for the caregivers of Alzheimer’s disease patients have been observed in two cities over a period of three years. One support group was sponsored by a day hospital for Alzheimer’s disease patients, being a component of its research program on caregiver functioning. ADRDA-sponsored support groups also were observed. In one city, participating adult children and spouses were separated into different groups; in the other city, various family caregivers met together. Throughout the fieldwork, caregivers were interviewed periodically in both home and respite care settings.

The study attempted to maximize variation in the social composition of the participating groups and population. Support groups comprised both member-facilitated and professionally facilitated leadership, and both didactic and self-help orientations. Participants included male and female caregivers, differently related to patients, drawn from a wide range of educational and occupational backgrounds. Because Alzheimer’s disease victims tend to be elderly, the risk varying with age, caregivers themselves were mostly middle-aged or elderly. The Alzheimer’s disease literature

suggested that the study population's social composition reflected its general counterpart. Still, it was not so much representativeness that warranted the study's utility as it was the contribution of its data to understanding the interpretive quality of responsibility and the data's related critique of the prevailing static model of caregiver functioning.

In this article, attention centers on the discourse of family responsibility and caregiving. The analysis highlights four features of related interpretive activity. First are the social comparisons that serve the interpretation of responsibility. Second is the place of issue contingency in the evaluation of support. The third, family history, concerns how traditional family understandings affect the assignment of member responsibility. The fourth, kinship priority, shows how multiple familial linkages with a member affect the definition of caregiving responsibility. The analysis of the first two features serves as further commentary on the relative unimportance of impairment for caregiver functioning; the analysis of the second two draws attention to the dynamic meaning of heterogeneity in family caregivers. All references to persons and places are pseudonyms.

#### SOCIAL COMPARISON

Kinship did not define responsibility as much as it was used to interpret it comparatively. Field data showed that the question of who was responsible for the continued care of the Alzheimer's patient did not settle on the caregiver's formal kinship with the patient, or on its presumed obligations. Nor was it directly evident how a caregiver's support served the caregiving function. Rather, the interpretation of responsibility in relation to kinship was articulated through social comparisons.

In sharing their experiences, caregivers used what they learned about kinship and support to assign meaning to their own sense of responsibility. Time and again in the support groups studied, it was evident that any network of kindred could be defined as responsible against one standard of comparison and irresponsible against another.

Consider the typical experience of a caregiving husband I called Hal. He had been retired for years before his wife, Sonia, began to show signs of forgetfulness and confusion. She was diagnosed as having Alzheimer's disease. As her symptoms worsened, Hal sought the help of his

four children in caring for Sonia at home. Living nearby, the children organized a rotating system of respite duty, each taking their mother into their own homes for short stretches of time. One of the children, a social worker, put Hal in contact with a local support group for the caregivers of patients with Alzheimer's, which Hal eagerly joined.

From what Hal shared with others in the support group and from what he conveyed at home, it appeared that he had a very responsible family indeed. Several support group participants marveled at the way "everyone pitches in." Yet, while Hal described what seemed to be a viable system of support, he initially cast aspersion on the children's irresponsibilities. The degree of support he received and reported in detail did not mean to him that his children were showing adequate filial concern.

In the course of attending the support group meetings, Hal encountered the related experiences of others. Some were similar to his, with various family members dividing the burden of care. Others differed, being networks of kindred who kept contact with the caregiver but refrained from participating in caregiving. It was evident in Hal's continuing testimony and comments in support group proceedings that he soon took the similarities and differences into account in evaluating his own children's contribution to Sonia's care. Indeed, on one occasion, confirming what seemed to be an emergent consensus over the benefits of "good children," Hal tellingly recounted:

I'd have to say that my kids have been pretty darn good to me. I know that I haven't always said so and maybe I didn't use to think that. But when you see what you got, you have to be thankful for your blessings.

Another participant, Marge, added:

That's right. You sure do have good kids. You better believe it too. Compare them to my kids. You'd think they'd stop in and see their father sometimes or even take him out somewhere. But no, never. [Turns to Hal] You can't complain, Hal. You can't say that you've got it bad.

Hal responded:

I never said that they weren't good to me. It's just, well, it's just that sometimes you don't know what you've got until you find out that some of them are worse off than you. That's all. Sure my kids are concerned.

Support group participants often detailed others' contributions to their caregiving activities. As they did so, they learned of the possible mean-

ings of kinship and caring. As Hal did, they used what they learned to define the place of their own kindred in managing the burdens of caregiving. It was not uncommon for participants to state that they “saw things in a new light” or “in a different way” when they learned of others’ experiences. Participants were regularly reminded of their own changing views, in which case their earlier feelings and attitudes became comparative standards of judgment for later ones.

Not only were evaluations of individual family responsibility embedded in comparisons of kindred, but a caregiver’s own sense of filial responsibility was likewise articulated. A persistent question in the support groups concerned when “it’s time,” referring to when it was time to decide to end home care and initiate institutional placement. The phrase raised the portent of abandonment and filial irresponsibility, of loss and disloyalty.

As participants conveyed their thoughts and feelings regarding nursing home placement, they typically considered what kind of wives, husbands, sons, daughters, sisters, or brothers they were. They formulated answers both in relation to their individual life histories with the patient and in comparison with each other. For example, in one of the support groups, participants personally knew of, and repeatedly matched themselves with, someone who was said to be a “totally selfless and devoted wife.” The devoted wife cared for her demented and vegetative husband at home despite his no longer knowing her, being bedridden, and his lack of control over bodily functions. The devoted wife was cast as a virtual martyr, the living exemplar of a truly responsible spouse who, according to reports, would look after the impaired husband “until the very end.”

Participants who vowed to persist in caring for a spouse at home often compared their marital responsibility with that of the devoted exemplar. Their proximity to this ideal was used to assign meaning to their own kinship and responsibility. As one wife remarked in such a comparison:

If it gets to that point, I’ll do what I can, just like her [the exemplar] I hope. If I can be even half the wife she is, then I think I’ll have done as much as anyone could.

There was no shortage of positive exemplars against which to evaluate the meaning of one’s kinship and to discern the substance and limits of responsibility. Some, like the near-martyr, were

local standards of comparison. Others, like now-deceased Rita Hayworth’s caring daughter Yasmin Aga Kahn, and Bobbie Glaze, both renowned Alzheimer’s caregivers and active in the ADRDA, were nationwide celebrities recognized and referred to in many support groups, local ADRDA chapters, and chapter newsletters. Indeed, all caregivers served as exemplars as their known or past experiences became momentary or even legendary sources of personal comparison in matters of kinship and responsibility.

With a change in usage, each positive exemplar—each ideal caregiving wife, husband, adult child, or sibling—stood to be a negative testament to one’s experience. For example, on one occasion in the preceding support group, the wifely martyr was transformed into a negative standard. One of the men attending, who cared for his demented spouse at home, raised the question of whether caregivers who agonized over institutionalization weren’t being too hard on themselves. He suggested that by comparing themselves to the ostensible martyr, they were attempting to do something that “very few of us mortals could, really.” As he explained:

Maybe we’re being unrealistic about this. As far as I’m concerned, I can’t see myself doing that for Vivian [his wife]. Very few of us mortals could, really. It’s not that I don’t love her. It’s just that when it’s time, it’s time. There comes a point where you just have to face facts. They get to the point where they don’t even know you. If you ask me, I think Lorraine [the martyr] is denying the obvious—that her husband is just an empty shell. To keep on acting like he’s still there, to me, is not being realistic. When Vivian—God bless her—gets to that point, I’ll just have to let go. [His voice cracks with emotion.]

A change in the standard of judgment soon cast what was formerly Lorraine’s impressive devotion into unrealistic denial. Those in attendance did not catapult wholesale into the acceptance of the new way of thinking. But it was evident in the discussion following that each participant’s own sense of familial responsibility was complicated by how each chose to interpret Lorraine’s activity and alleged devotion.

The qualitative analysis of social comparison in the interpretation of family responsibility and caregiving did not, of course, deny the effect of social support on the risk of institutionalization. But it did reveal the effect’s complex meanings, showing how perceptions of support could vary against a range of related considerations. It was

one thing to know that, say, an Alzheimer's victim has a living husband to care for her at home and that, according to pertinent studies (cf. Johnson and Grant, 1985: chaps. 3-4), the victim has a relatively low risk of institutionalization. It was quite another to conclude that the husband will act like one, whatever that might mean to those concerned. Social comparison figured significantly in sorting this out.

#### ISSUE CONTINGENCY

The interpretation of responsibility and caregiving also showed an "it depends" quality related to particular caregiving issues (cf. Gubrium and Lynott, 1987). There were times when respondents expressed this pointedly, reacting to inquiries about the degree of their patient's impairment or the factors that influenced their felt burden with the phrase "it depends." Typically, they proceeded to explain what their opinions and related sense of responsibility depended on. At times, the "it depends" quality was implicit. When a respondent detailed the importance of family support in caregiving at one point in testimony and cited its disadvantages at another, I was compelled either to give credence to an "it depends" feature or conclude that the respondent was inconsistent. The context of responses regularly suggested the former, the issue contingency of opinion and sentiment.

Consider the finding that the felt burden of caregiving is affected more by the social support network of the caregiver than by the actual degree of impairment (Zarit et al., 1980). It is said that caregivers whose families take an active interest in the burdens of care and, for example, routinely visit the household ostensibly feel less strain than those without family contact. One might presume from this that family visitation lessens the risk of institutionalization. Yet a consideration of the meaning of contact and visitation reveals that "responsibility" discerned in this way can have diverse interpretations.

This was apparent in a caregiver's, Bernice's, account of the family side of caring for Peter, her 82-year-old, demented husband. Bernice was a frequent participant in one of the support groups studied. Her group participation and interview data showed that, like others, caregiving issues served to define differentially the advantages of

contact and visitation for her. Her sense of advantage in having a "supportive" network depended on the issue or side of caregiving considered.

The physical and functional burdens of care were discussed often in support groups. Caregivers compared notes and offered each other tips on how to deal with issues such as getting through the night without being awakened by a wandering patient. The need for help in managing activities of daily living like dressing and feeding the patient and the desire for respite care were other concerns. Family relations and support took on their advantages and disadvantages according to issue, not generally from the evaluation of the caregiving burden or the family network as a whole.

As others did, Bernice compared her own circumstances with coparticipants and acquaintances. She repeated her belief that as far as easing the burden of daily care was concerned, family responsibility was imperative. Being responsible was exemplified in many ways. It was said to be evident in the way Horace's daughters, for example, took turns coming into Horace's home to help with household chores and the demented wife's daily cares. It was obvious in the way another Alzheimer's victim, Catherine, who had never married, was a shared burden and ward of her two sisters, who housed and boarded her. Bernice often commented that these were ways a family should act; the specific comparisons informed her of the responsibilities of being kindred.

Bernice believed, too, that her husband's family paled in comparison. She pointed out that it was no wonder that some caregivers had to "just give up," meaning seeking a nursing home placement for the patient. Concerning her own situation, Bernice once explained:

Well, I'd never place him [husband] in a nursing home—just as long as I can take care of him on my own. Believe you me, though, it takes a lot of willpower and determination. If I had just half the strength I do, his families' lack of concern would've been devastating. You do wish they'd come around and give you a hand once in a while.

As far as the issue of such concrete support was concerned, Bernice felt abandoned, her family considered totally irresponsible. As she noted, if it were not for her personal resolve, her husband would no doubt have been institutionalized.

Bernice's line of reasoning and sentiment about family responsibility reflected the available

research wisdom up to a point. During a home interview, Bernice picked up on what she had learned about the possible hereditary aspect of Alzheimer's disease in complaining about the lack of family involvement. Asked whether all family members knew about her husband's Alzheimer's diagnosis, Bernice responded:

Sure. Well, I think they do. But if I was his brothers and sisters, let me tell you I'd be a heck of a lot more interested in it. Especially when I tell them it's a familial disease. Cause they don't, you know. All they do is say, "Bern, you're doing a good job," pat me on the back, and that's that.

At the same time, Bernice reported that she "felt bad" that the family didn't seem to care as much as other families did. As she often conveyed in support group sessions, she might appear not to be bothered, but there were moments when she got "real bummed out" about it, as she put it. If the lack of concern continued too much longer, she felt she might have to give up on her sick husband altogether.

Now compare Bernice's sentiment, opinion, and possible action with their counterparts when the question of family contact, responsibility, and caregiver stress was entertained against the issue of family interference. It was not unusual in the support groups studied for the annoyances of meddling children, siblings, and spouses to be lamented as part of the stress of caregiving. A facilitator once framed family responsibility in this way:

Those are the kinds of dynamics you get when families are involved. Each one is concerned that he or she is not being family-like. They all try to get in on the action . . . you know, for the good of the patient. But what happens is that they start getting on each other's nerves. They can't leave well enough alone. But they can't get involved too much, either, and that makes trouble.

Like others, Bernice herself had considered the matter, both in her support group and in personal testimony. When she did, her comments and sentiments about family contact were at considerable odds with what she expressed when the issue addressed was concrete caregiving. Indeed, on one occasion, she asserted that she was glad that John, her demented husband, had the kind of family he did, one that stays clear and never bothers to interfere in caregiving. Bernice reported that she couldn't stand it if she had to contend, day in and day out, with the kinds of

close and, as she put it, "so-called supportive" families some of the others had. Reflecting the facilitator's comments, she concluded that no one needed that kind of family:

You know, when you think about it, if I had had to deal with his family day in and day out and all, I might have just given up on John by now. No one needs that on top of everything else. If I know them, they would have fallen apart [if they had taken over caregiving] and John would have been in a nursing home before you could yell "Tiger."

Comparing her own lack of family contact with that of another support group participant, Bernice explained in a home interview, "I'm blessed with that because I, you know, I answer to no one. You know, there's no one here telling me what to do." As such, Bernice suggested that, for some sides of caregiving, a "responsible" family might be an unresponsive one.

What we find in these contrasting comments and sentiments about family contact, support, and responsibility is that their practical meaning to those concerned is issue-contingent. It was not that Bernice was being contradictory or providing uncodeable testimony. Rather, her personal responses and group contributions showed continual evidence of having an "it depends" quality. A survey of opinion would not have readily discerned the complication. Qualitative analysis provided empirical reason to believe that, depending on the issue, "responsible" families could be both nonsupportive and desirable.

#### FAMILY HISTORY

While it has been shown that the relationship between felt burden and the decision to seek institutionalization for an Alzheimer's patient is less related to the degree of impairment than it is to social support and family caregiving roles, the quality of the latter has been given only cursory attention. Researchers have distinguished network configurations and kinds of family caregiving roles (husbands versus wives, adult children versus spouses, the unmarried versus the married) for their comparative responsibility and effectiveness. But the comparisons have been rather static, matching particular roles with functional effectiveness. In this section and the one following, complications of family history and kinship priority are addressed in further consideration of the interpretive heterogeneity of caregivers.

As far as family history is concerned, it was evident in what caregivers shared and reported that families entered into the caregiving side of the Alzheimer's disease experience in accordance with past habits and expectations. Family history confounded the ingredients of positive caregiver functioning, making it difficult to draw straightforward conclusions about, say, the childless unmarried as opposed to the childless married regarding effective caregiving.

Consider the distinct qualities of ostensibly comparable familial networks and roles when family history is taken into account. In sharing with each other what their families were like as responsible kindred, caregivers frequently described their kin in terms of what I'll call "family types." Family types are a common usage, two types being the "black sheep" of the family and the family "favorite." Their usage by caregivers was of more than anecdotal interest, for their individual application as recognizable, shared categories provided an important means of explaining similarities and differences in the caregiving experience. Family types were part of native reasoning, used to explain, say, why identical formal kinship bonds with a patient figured differently in the commitment of caregiving.

Take two wives of Alzheimer's patients, Mamie Klein and Kate Johnson. In their support group, they frequently spoke of how similar their circumstances were. Both had married their current spouses late in life, after previous marriages had ended with the husbands' deaths. Neither had borne children of her own, but both current husbands, now Alzheimer's victims, had children from previous marriages. In both cases, the husband's adult children and husband's siblings lived in the same city, many nearby. All in all, as compared with other support group participants, Mamie and Kate had a surfeit of available family linkages.

According to both Mamie and Kate, it was evident that the two families, by and large, were friendly. Mamie put it this way:

They're a real big gang, those Kleins are. They get together a couple times a year for a big bash. They're always at each other's places and doing for each other. One big fat family, you might say.

Likewise, Kate described her kindred, the Johnsons, as "all over town and really a very close family."

The similarity belied a certain distinction pertinent to the issue of family responsibility: a history of different relations their respective husbands had with otherwise comparable families. The similarity stopped short of the different family types their husbands represented. It was well known in Mamie's support group that her husband, Jake, was the family's black sheep—someone who, according to Mamie, "always had his own ideas about things and went off and did things none of the others were brave enough to do." All participants had heard more than once of how Jake had reaped the unfortunate consequences of this family status, how he was considered haughty and too political by his siblings, even his own children, and how he was isolated and ignored. Kate, in contrast, marveled at how indulgent her husband's, Keith's, siblings were, and at how they took an active interest in his care, never ceasing to offer help. While Kate did not specify whether Keith was the family favorite, she often noted that "they really think the world of their brother."

Both Mamie and Kate embedded their accounts of kin relations in family history. While Mamie recollected a detailed past of sour contacts with the Klein family, Kate went into equal detail about the Johnson family's tradition of support. Just as Mamie pointed out how Jake's being the family's black sheep affected her from the very beginning of her marriage to Jake, Kate reported the many times past she had been grateful for Keith's family's help and friendship.

One might conclude from the comparison that, subjectively at least, Mamie had an existing but personally ineffective family network while Kate had a supportive one. This would serve to separate the concept of network from network costs and benefits. It would ostensibly make Mamie's family relations more like Betty's, for example—a caregiver who was an only child and whose husband's siblings had passed away years before the onset of his dementia. Betty and Donald, her husband, had no family to speak of. According to Betty, she was on her own and "making do as long as I can." In contrast to Kate, neither Betty nor Mamie had an effective family support system and would be expected to be prime candidates for the stress believed to result from the burdens of caring for a demented patient on one's own.

However, careful attention to the diverse qualities that family history brings to the caregiving experience suggests that the similarity would be forced. While Mamie and Jake were virtual family isolates, Mamie's long-time, deep resentment of the way her husband had been labeled and treated by his family had generated an equally deep resolve to "go it alone," as she was in the habit of saying. She had indicated that she had always felt like an outsider in *that* family—her personal counterpart to Jake's status as black sheep.

Support group participants encountered an anger in Mamie that many believed fueled her determination not to put Jake in a nursing home. A support group facilitator once made the following observations, half didactically and half in jest, playing on the black-sheep theme:

I hear your anger, Mamie, and I can see how it's just built up over the years. You sure are the outsider. That sort of thing is a long time in coming, though, and you can't change it overnight, if at all. I guess we all have to live with our pasts. But, you know, there's a bright side, too. I mean if you can't say much else for the family at least you can say that they've kept you mad enough over the years to keep on fighting. And that ain't all bad for an outsider . . . or a black sheep.

Irv, a caregiving husband, commented on the observation, also somewhat in jest, as he informed Betty, "Now don't you wish *you* had a black sheep in the family to keep *you* going?" The chuckles all around were sobered when Betty responded:

That's not so funny as you think, Irv, because I really don't have anyone to turn to. All I've got to think of day after day is what's happening to me and what's happening to him [her husband]. That's it.

A consideration of family history offers a lesson about past and current categories of experiences in relation to family differentiation in caregiving. It informs us that people have their own ways of assigning meaning to parts of everyday life. They partition and assemble their lives on their own terms, against their pasts, in ways that might be at odds with the categories we might, as social researchers, use to analyze their contemporary experience. In Mamie's case, qualitative analysis presented the positive consequence of a tradition of negative family relations: a long-term lack of social support from a network of kindred was combined with a determination to obviate the

network in successful caregiving. Mamie was determined not to institutionalize her husband, but for a reason different from what her contemporary categorization as either support-system-poor or support-system-rich might suggest.

#### KINSHIP PRIORITY

Another interpretive complication bearing on the heterogeneity of family caregiving is the dynamics of kinship priority, along with its shifting sense of responsibility. The complication centers on the configuration of family roles that any one member has with others. A wife is often also a mother and a sibling; an adult child may be a parent in his or her own right, as well as a sibling. When a family crisis occurs that has the potential of attracting the concern of diverse family members, the question of responsibility hinges on how the varied role relationships in one's configuration of roles are assigned priority. In the matter of caring for an elderly victim of Alzheimer's disease, the issue of who the caregiver is, or caregivers are, may require a decision about, say, whether one is an adult child to one's parents first or a parent to one's children before all.

The research literature in this area does speak to the issue, but again in a rather static fashion. Shanas's (1979a, 1979b) survey data suggest that a "principle of substitution" determines caregiver selection, with kinship priority operating according to formal familial distance from the member concerned. For example, when a married husband with adult children is stricken, chances are that the primary caregiver will become his wife. If the wife is unavailable, the children will step in next, and so on.

One problem with the principle is that it is a theoretical construct culled from survey data, the analysis of which is most sensitive to statistical variations that may or may not be substantively significant. While such data are suggestive of social organization, they do not bring us face to face with it. If a principle of substitution indeed statistically organizes kinship priority and responsibility, it tells us little or nothing about what it means in practice. Another problem is one raised by Johnson and Catalano (1981: 611), who state that the principle may be too optimistic. They challenge the assumption that one source of support is enough. We might add that the challenge is much broader. If a principle of substitution

operates, a good deal of activity must occur to sort out and align its raw material—who should care for what or whom and why—which pertains not only to informal kindred but to the sense of familism with others (Gubrium, 1987). Kindred not only must assign their caregiving responsibility in serial fashion, if in fact this happens, but must also articulate its rationale against many challenges, four of which are focal in this paper.

Qualitative analysis provided a means of gaining access to the raw material. The support groups studied, in particular, virtually displayed the dynamics of discernment that construct kinship priority, showing evidence that discernment was far from an automatic matter of substitution. All participants, of course, did recognize a version of the substitution concept, for they regularly spoke of “what would happen if” an existing primary caregiver, usually themselves, were to become ill or unavailable. Who would then “take over?” But it was not something separate from social comparison, issue contingency, and the cognizance of family history. Nor was it something settled once and for all by the actual presence of the patient in a “priority” household. While a family might have emulated the principle of substitution in the household placement of the patient, it did not necessarily mean that judgments of effective caregiving or proper filial responsibility followed (cf. Gubrium and Holstein, 1987).

For some, the fact that an adult child, such as Lydia, devoted so much time to her demented and widowed mother's care despite having a family of her own, showed filial responsibility. It was the appropriate thing to do, given the unavailability of a caregiving husband. But, for others, the devotion came at the expense of Lydia's own husband and children, something that could be taken too far and should rightly be balanced against other family priorities. As such, kinship priority was as much a question of how to figure competing familial responsibilities and allegiances as it was a principle of substitution operating between someone dependent and a fund of possible family caregivers.

Support group participants regularly shared their concerns over how the burden of care was affecting their relations with others. For many, what “others” meant was formal kindred. For some, it meant close friends and confidants. The diversity went well beyond the primary formal

familial horizons of the principle of substitution. Whoever others were, there was almost always a contending familial component of sorts in the balance, whether that was a felt responsibility to formal kindred other than the patient or responsibility to those believed to be equally real quasi-kin (Gubrium and Buckholdt, 1982).

Describing the impact of caregiving on relations with a long-time, best friend, a never-married adult child, Gilda, who served as her demented mother's caregiver, explained:

June's my best friend and like a sister to me. Taking care of Mother takes all my time away from June and I feel really bad about it. I know it's hard on June. It's hard on me! On everyone. But I have to think of Mother too. I guess it's the right thing to do. Some of them [support group participants] say it isn't fair to me and that the rest of the family [her married siblings] should do its part. Sometimes I wonder who'll take care of Mother if my own health starts to go haywire.

It was evident in this caregiver's comments, and certainly clear in related support group proceedings, that feelings of responsibility informed a common concern with family caregiving. One thing that being family meant was being responsible to members. It was evident, too, that a concept of substitution framed questions about the limits and dilemmas of family responsibility, of how much one could do, who should do it, how long one would last, and who would take over afterward. But the concern over who would, or should, substitute for whom, together with related sentiments, was a matter of opinion and debate, just as evident in its repeated discussion in the support groups in general as it was present in Gilda's comments.

In application to caregiving and formal kindred, the principle of substitution deemphasizes the place of quasi-kin and unrelated significant others in the interpretation of responsibility. As was evident in Gilda's attempt to balance the responsibilities of being kin and quasi-kinship, Burnley (1987) has suggested that the kinship priority problem is not the exclusive property of the married but is experienced by singles too. The lack of formal marital and parental bonds of one's own may be used against singles who, according to Burnley, risk being cast as filially irresponsible if they dare to equate their concern for the competing sentimental priorities of intimate friendship with obligations to spouses and children.

## CONCLUSION

Field data and qualitative analysis show that family responsibility and caregiving are not only sensitive to interpretation but subject to continuous review. It is evident that an interpretation by any one caregiver or family member is tied to others, which suggests a limitation of individual measurement. Moreover, what it means to effect family responsibility is articulated against the possible things it once did, or could, mean to those concerned.

It is important to note that the lessons of qualitative analysis are not a plea for anecdotal usage. Qualitative analysis emphasizes the same general categories of human experience as other forms of study. Its lessons derive from the aim of being sensitive to the diverse ways in which commonplace categories can be construed and assembled. Each case, while unique in a certain respect, is a product of the general social operations—the dynamics—of understanding. Each case is an ensemble of what Alzheimer's caregivers take their experiential particulars to depend on, four considerations of which are social comparison, issue contingency, family history, and kinship priority.

Qualitative analysis has a bearing on intervention. As far as the Alzheimer's disease caregiving experience is concerned, it informs us of the need to take into account not only what the social side of caregiver functioning impresses on the experience, such as how family support networks make a difference in felt burden, but how the social side is meaningfully articulated in practice. It suggests that those concerned not be taken as passive by-products of the social factors, but seen as continuously learning the possible meanings of their experiences, bringing a wide range of individual interpretations of social relations and effectiveness to our attention.

In one sense, qualitative analysis offers what working service providers have always at least tacitly known, that is, the importance of the case as a unit of analysis. The relevance of the case, however, is understood to be what its particular ensemble distills out of qualities and processes general to all, not uniqueness as such. While, in a certain respect, service providers must treat the particulars of each case as belonging to it alone so as to facilitate concrete intervention or casework, at the same time the field data have shown that

the character of individual cases is understandable only in terms of general principles of human action—among them, social comparison, issue contingency, family history, and priority.

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