MEASUREMENT AND THE INTERPRETATION OF BURDEN IN THE ALZHEIMER’S DISEASE EXPERIENCE

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ABSTRACT: Three components of the Alzheimer's disease care equation are considered: impairment, felt burden, and the institutionalization decision. Measurement and the results of existing studies are compared with field data on the descriptive organization of the caregiving experience. It is suggested that measurement is an inappropriate language for depicting the experience, empirically distorting what is otherwise a practical process of definition and interpretive transformation, shaped in, and constrained by, caregivers' continuing attention to the meaning of their burden.

In the last decade or so, a research literature has emerged dealing with the burden and stress of being a caregiver. The shift from primary attention to the patient's treatment and illness behavior to equal concern for the caregiver's well-being is part of increasing public wariness over the human and financial costs of institutionalization. The care equation—to be considered against the care experience—now has three components: (1) the patient's presenting condition; (2) the perceptions, feelings, and resources of caregivers, family members, and significant others; and (3) the question of institutionalization versus home care.

Most studies of the burdens of care have dealt with the impact on family members of caring for the mentally ill at home (Brown, Birby, and Wing 1972; Grad and Sainsbury 1963, 1968; Kreisman and Joy 1975; Lefton, August, Dimetz, and Pasamanick 1962; Thompson and Doll 1982). Recently, the relatively large population of Alzheimer's disease (senile dementia) victims and the disease's growing recognition have turned researchers to the effect of the dementia on the family (Montgomery, Stull, and...
Borgatta 1985; Morycz 1980, 1985; Poulshock and Deimling 1984; Robinson 1983; Zarit, Reever, and Bach-Peterson 1980). By and large conceived as an equation, the separate components of the care burden are measured, the components covaried, and the meaning of caregiving thereby distilled.

Studies of the burdens of caring for Alzheimer’s patients do differ in terminology and method. While most distinguish so-called objective from subjective burden, there is terminological overlap. Zarit et al. (1980), for example, describe the subjective side as the “felt burden,” measured by a 29-item, self-report inventory administered to the primary caregiver. Objective factors, considered for their association with feelings of burden, include the patient’s mental status, functional ability, and behavioral problems. Poulshock and Deimling (1984) refer to the patient’s presenting mental and physical problems as “impairments,” distinguishing them from “burden,” which is the caregiver’s estimate of how personally tiring, difficult, or upsetting the impairments are. This is further distinguished from “impact,” the related material and social consequences of caregiving, such as financial hardships and disrupted familial relationships. Morycz (1985) prefers to differentiate external factors or events, called “stress” or “stressors,” from “strain,” comprising the cognitive, affective, and physiological byproducts of stress. He uses strain, felt stress, subjective burden, and perceived burden interchangeably.

Diverse conditions alter the relationship between presenting problems, caregiver responses, and the institutionalization decision. Zarit et al. (1980, p. 654) conclude that informal support networks may reduce the likelihood of institutionalization by mitigating the effect of overwhelming burdens on the caregiver (also see Zarit et al. 1985). Morycz’s (1985) multivariate analysis indicates that a variety of “antecedent” and “background” variables, such as the availability of back-up help and the patient’s marital status, affect the desire to institutionalize (the dependent variable) stemming from strain (the independent variable). Montgomery et al. (1985) suggest that an even more general system of variables would serve to better discern burden and its consequences, especially the time element. Deimling and Poulshock (1985) conclude that factors other than the absolute level of impairment, particularly precrisis caregiver attitudes concerning the suitability of nursing home care and the personal well-being of caregivers themselves, predict institutionalization.

Yet, despite its admitted complexity, the substance and linkages of the burden of care, as conceived in existing studies, remain at a considerable distance from the practical experience of those concerned. Complexity is discerned in the number of variables that enter into the caregiving equation, which, as Deimling and Poulshock (1985, p. 574) put it, “operate to determine” the organization and auspices of care. Unrecognized are the experiential dynamics and transformations of individual variables, such as the everyday leaps in meaning assigned to stress, perceived burden, or institutionalization. Stress, for one, can, on occasion, be a sign of successful endurance and, on other occasions, be designated depressing in a single individual. While Zarit et al. (1980), among others, have noted that impairment has no straightforwardly adverse effect on felt burden, the statistical conclusion ignores the situated, “undetermined” complications of the relationship.

This article reports the results of a field study of the descriptive organization of caregiving, part of a larger project dealing with the form and substance of the Alzheimer’s disease experience (Gubrium 1986). The study concerns the organization of
meanings assigned to the diverse variables recognized as significant components of the burdens of caregiving. While it does not, of course, discredit the suffering entailed, it shows how much broader the component horizons of the caregiving experience are than existing studies permit them to be, seriously challenging the language of measurement and related care equation.

**APPROACH AND METHOD**

The language of measurement is characteristically subject to what critical theorists call "identity thinking" (Held 1980): the isolation of parts of experience from other portions for the purpose of pinpointing their separate values. For example, measures or assessments of the burden of care aim to isolate that particular variable from others, such as strain, for the purpose of evaluating their respective statuses in order to subsequently trace their interrelationships—what Blumer (1956) once critically examined as "variable analysis." While variables, of course, do vary, they are nonetheless conceived and denoted as distinct entities, as burden or strain or background or support networks, and so on.

Close inspection of the way the ostensibly separate entities enter into the practical experiences of those concerned suggests that their reality statuses are interwoven, not as multivariate correspondences, but as mutually constitutive. For example, when a caregiver is asked what his/her felt burden is in caring for his/her demented wife/husband at home, she/he, like others, organizes his/her response against an "occasioned" sense of the variable, commonly evidenced by the typical response that "it depends." While the burden of care might not change its factual status, its meaning depends on how it is being considered. At times, the caregiver reports the feeling of being overburdened and depressed by his/her impairment; at other times, it is reported that he/she feels differently. Accordingly, the objective impairment itself, to which he/she responds, takes on its experiential meaning against the interpretation of his/her feelings. As practical features of experience, it is not just that impairment and felt burden covary, but that they are mutually transformed, altering their qualities in relation to each other. In just a few moments' consideration, the felt burden defined against what is perceived as overwhelming impairment might shift, as it did in one caregiver's estimation, to "not burden really, but just those daily irritations" when compared to the "really frightening picture" presented by another caregiver's victim. As such, the felt burden and level of impairment evident in any caregiver's experience "depends" on the occasion, situations, and comparisons taken into account in their interpretation (Dingwall 1976; Filmer, Phillipson, Silverman, and Walsh 1972; Garfinkel 1967).

The "it depends" quality of experience is not idiosyncratic. It is a regular qualification of casual commentary on experience, just as it is a commonplace, sometimes methodologically unnerving, feature of survey respondents' testimony. Unfortunately, it is an uncorrectable feature of measurement that it systematically, but nonetheless exquisitely, describes the variations of distinct variables, not variable cotransformations that "depend."

Rendering measurement to the description of variables, we are left with the need for a language and method by which to approach the practical, "it depends" quality of experience, including poignant considerations that enter into concrete interpretations of
the burden of caring for Alzheimer's disease victims. Such data become available when
we address the process of interpretation as part and parcel of the experience being
considered; burden, impairment, strain, support, and the like, are taken to be as much
meaningfully assigned entities of experience as they are objective conditions. The
method follows from the approach, requiring explication of the process of interpreta-
tion. The procedure is to analytically describe how those concerned—service providers,
caregivers, significant others—achieve understandings and, in the process, form and
transform the meaning of caregiving.

Participant observation of support group proceedings provided a means of gaining
access to the interpretive complexities of the burden of care. The Alzheimer's Disease
and Related Disorders Association (ADRDA) sponsors support groups for caregivers in
over 120 cities across the country, some being part of statewide networks of chapters and
satellites. Data were collected in ADRDA-sponsored support groups in two cities.
Support groups in one of the cities were distinguished by their member facilitation and
the separation of caregiving spouses and adult children. Support groups in the other city
were regularly facilitated by service providers, commonly social workers, and did not
separate caregivers. Also studied in one of the cities was a support group for the primary
caregivers of patients in an Alzheimer's disease day hospital, housed in a larger acute
care facility and facilitated by staff members. Part of the day hospital's research program
entailed assessing perceptions of impairment and the burden of care, which were
frequent topics of discussion in its support group. Discussions offered direct evidence of
the interpretive transformations of burden measurement (cf. Cicourel 1964).

IMPAIRMENT

However termed, existing studies of the burden of care distinguish the objective facts of
impairment from the felt burden. Impairment refers to the physical and mental incapac-
ities of the Alzheimer's patient. As an identifiable entity, impairment is hypothesized to
have a causal impact, usually negative, on the caregiver's feelings and perceptions,
even his or her physical condition. There are well-known means of assessment, the
most familiar being the various mental status questionnaires (MSQs) or examinations
(MSEs) (Folstein, Folstein, and McHugh 1975; Kahn, Goldfarb, Pollack, and Peck
1960; Pfeiffer 1975b). Some impairment measures focus on the patient's functional
capacity, the ability to complete so-called activities of daily living (ADLs) such as
eating, voiding, and grooming (Lawton 1971). The widely used OARS interview
(Pfeiffer 1975a) combines mental and functional assessment in a multidimensional
battery. More recently, Deimling and Bass (1986) have stressed the need to differen-
tiate cognitive incapacity from social functioning and disruptive behavior in measuring
erlier impairment. Whichever measures are used, results are compared with assess-
ments of other components of the care equation, the multivariate analyses of which
ostensibly provide evidence of the logic of caregiving.

All caregivers who participated in the support groups studied were acquainted with
some form of the measures. Most had received the results of the MSEs routinely
applied in physicians' mental and physical examinations of their patients. Many care-
givers had been apprised of the results of quantitative assessments of their patients'
functional capacities. The 9–12 caregivers who participated in the day hospital's Alz-
Alzheimer's disease research program were presented the outcomes of repeated assessments of their patients as well as the results of their own responses to the burden of care.

Test administration in the day hospital's research program took three forms. Each patient's mental functioning was directly assessed in periodic cognitive evaluations by a research psychologist or a trained nurse. Caregivers' individual perceptions of impairment and their responses to the burden of care were regularly evaluated by the day hospital's social worker. Semiannually, while assembled, caregivers were administered an extensive battery of tests and questionnaires dealing with patients' mental and physical functioning, caregivers' life satisfaction, and felt burden.

While the day hospital's testing program was not limited to any one research instrument used in existing studies, test items dealt with the same matters and were similar, often identical, in phrasing and response organization. Item for item, the day hospital's caregivers and patients encountered the broad range of inquiries addressed in popular MSE/MSQs and functional assessment batteries.

In their support group, the day hospital's caregivers frequently commented on their own and their patients' test experiences. While their acquaintance and interaction outside test situations might raise questions about the individuality of their test responses, at the same time, it provided an opportunity to learn how they interpreted select items and the overall tests presented to them. What do caregivers' encounters with this knowledge tell us about the meaning of impairment?

**Awareness and Impairment Construction**

On one occasion, a few days after caregivers had completed a lengthy questionnaire dealing with their patients' functional capacity, the day hospital's support group proceedings turned to the meaning of select questionnaire items. Following a lively exchange of opinions about the degree of impairment anyone could tolerate before "something had to be done about it," one of the participants, Sam, commented:

Ya know, that reminds me of something I wanted to say but forgot about. I'm not so sure what all those questions mean in that test there that we all had to take a couple of days ago. I was thinking especially about that one about if Peggy's [his wife, the patient] initiative has gotten worse lately. What bothered me when I was trying to think about it is that I don't really see that as having anything to do with the Alzheimer's. I don't know. Did anyone else get that feeling?

Another participant, Mina, whose mother had Alzheimer's, immediately chimed in and complained that, yes, she had had that same feeling, but about the whole thing, not just the initiative question. Her feeling was that, as she put it, "I hadn't really thought about many of them things about my mother until we were asked about it." In regard to her mother's grooming, Mina continued:

Mother's never been what you'd call a neat dresser, God bless her. Anyway, that never bothered me much until I started to ask myself if she could button her blouse right and put her hat on straight. You know what I mean? Sam, that question [related test item] started me to thinking and I've been thinking about it ever since then. And what's kind of bothering me, too, is if I'm just now making a big thing out of it because of that. But, you know, you try your level best to answer right.
In the conversation following, it was evident that each participant, in his or her own way, had considered the objective validity of test items as they applied to their patients' impairments, a repeated concern. Consideration centered on whether, on the one hand, select items turned their attention to real impairments they hadn't been aware of previously or, on the other hand, to impairments they now were reading into what actually were not problems at all.

Existing studies of the burden of care commonly treat the so-called objective burden or patient's impairment as an independent variable, both in the sense of its conception as a source of possible caregiver strain and as a separate and distinct factor in the overall care equation. The independence assumption, of course, is what makes it reasonable to explore the covariation of impairment and caregiver strain and, if modeled as such, to treat impairment as having an impact on strain, not the reverse. Yet it is evident in the foregoing exchanges that the independent, objective reality of the patient's cognitive and physical functioning was opened to question. In apparent good faith, caregivers wondered if what was otherwise described as impairment data were data of their own making.

Does the awareness raised by the measurement encounter produce impairment construction? While we are not prepared to answer yes or no, it is nonetheless evident that impairment cannot simply be treated as an objective condition, its accurate assessment left to the refinement of instruments. Those who engage assessment do not just convey the facts; they interpret the meaning of related inquiries against personal experiences. The awareness problem is dismissed at the risk of ignoring respondents' native theoretical and methodological wisdom into the status of knowledge about their own experiences. Short of that, the problem suggests that empirical access to objective impairment take into account its interpretive quality, loosening the relatively strict demands of measurement.

None of the support groups' caregivers were without concrete tasks of caring. When the awareness problem was raised, the issue for them was not one of the possible nonexistence of impairment, but how to construe what was obviously there. Support group proceedings repeatedly showed that impairment is tied to construing and, thereby, as much subjective as an objective state of affairs, as we will shortly show.

All concerned periodically warned each other not to dwell on the impairment too much, lest it become overwhelming. In the support group session described earlier, Mina commented rather pointedly about the connection when the discussion turned to personal reactions to patients' symptoms. Describing how she felt about all the tests and questionnaires she had completed, she remarked:

I'll tell you this much: the more I got into those things [tests], the more I got depressed. They made me feel like just about everything could be wrong with Mother and... oh, you know that she's forgetful, yes, but she gets along like the best of them. I mean, like, hey, what was I facing here? Like, if I thought enough about it, my mother did all of those things some of the time. Every time I take those things [tests] I come away feeling so blue and I get mad at myself because I let it get to me. They're only papers, not the real thing, anyway, not for me, anyhow.

Interestingly enough, Mina's remark suggests that what is or is not reality in the matter of impairment is as much located in her own feelings, as her feelings are responses to its objective burden.
This was not just a caregiver problem. Issues connected with impairment assessment were regularly raised by staff in the hospital's geriatric clinic utilization reviews (Gubrium, 1986, 1987). Staff members, including physicians who had administered MSQs as a regular part of medical examinations, geriatric nurse specialists, a psychiatrist, psychologist, social worker, and recreation therapists, periodically questioned whether their earnest attempt to assess and positively intervene into patients' and caregivers' lives was not itself leading them to see impairment everywhere. They repeatedly warned each other that the meaning of the impairment data available on each patient had to be interpreted against what else was known about a case. As such, like the caregivers whose diseased family members were the ostensible sources of their felt burden, staff members used particulars to assign meaning to the general, again casting doubt on the aggregative character of variable analysis.

Exemplary Comparisons

As caregivers participate in support groups, they gain rather detailed information about each other's patients. They also learn of the presenting trials and tribulations of yet other caregivers, from hearsay, ADRDA chapter newsletters, Alzheimer's disease caregivers' handbooks, frequently shown film documentaries and disease portraits, and chapter educational programming (Gubrium and Lynott 1985). Celebrities who now have or had the disease, like Rita Hayworth, Norman Rockwell, and Edmond O'Brien, together with their caregivers, combine with less-renowned disease victims and caregivers to provide a slate of comparable exemplars by which to evaluate individual impairments. The emerging history of each caregiver's assessment of his or her own victim's impairment, itself, serves as a continually changing background for interpreting the victim's later condition.

Consider how exemplars enter into the interpretation of impairment. In the day hospital's support group, caregivers not only exchanged information and feelings about the burdens of care but had become personally acquainted with each other's patients from regularly joining patients in a weekly social and recreation program. Week to week, caregivers were witness to several patients' conditions, a direct basis of comparison for assessing the mental and physical status of their own victims. Typical of support groups, this one, too, had developed its patient folklore. There were frequently repeated stories about "near vegetables," "plateaued victims," "very rapid declines," "wanderers," "particularly violent reactions," and "lucid moments," among other disease conditions.

On one occasion, during a discussion of the mental status examination scores of their patients, one caregiver, a middle-aged daughter, complained about the terrible burden her mother was getting to be. The daughter, Fern, reported that recent test results indicated that her mother had declined considerably in just the last few months, which, she added, her own experience corroborated. Fern turned to a participant seated next to her and asked, "Rose, haven't you noticed the same thing?" Rose responded that she indeed had noticed it, especially the mother's growing lack of humor, a woman who, it was generally agreed, had always had a smile on her face and appreciated a good laugh. Fern continued:
And the worst of it is, Rosie, that I used to be able to stand all the other things, you know, the folding [of clothing] and, you know, how stubborn she can be sometimes. It wasn't as bad at least when I could laugh at some of the silly things she did and she'd laugh, too. But it's not the same anymore. She still does all those same things but I think she's gotten worse because she's gloomy all the time. She's got that vacant look more and more, kind of staring ahead like they say Rita Hayworth does. It's a really, really heavy situation, and I feel it.

When another participant asserted that a patient's temperament figured significantly in the illness, the discussion turned to the general question of the relationship between functional impairment and patient mood in the overall burden of care. Participants distinguished patient mood from their own reactions. A husband, for example, commented that his wife's lack of expression made it all the worse for him, that he could, in his words, "take twice the wandering if she'd only be happy and laugh again."

Yet, an apparent consensus over the relative meaning of mood and physical functioning was soon to be altered as another caregiver, Milt, provoked the agreement with a different interpretation:

I wouldn't be too sure about that if I were you. That's not the way I see it. I don't know if I can place that much faith in the person's mood. It isn't all it's cracked up to be. I get sick and tired of all that happiness stuff and that "smile is your umbrella."

You all know Belle [his wife, the patient] very well and you all can see for yourself that she's the real joker and tease of the group [day care hospital patients]. She's a very social person. She's always been. Talking and always laughing, like you wouldn't believe. Well, I hate to say it, but it's just driving me bananas. The constant chattering and laughing at everything. It's gotten so's I wear my Walkman [radio headphones] whenever I'm at home and Belle's around. The only time I get any peace and quiet is when she comes here [the day hospital] twice a week. All that chatter and giddiness have made her a real handful. You should all thank God for small favors. I only wish Belle's mood were like your mother's. It would really lighten the burden. It's not me, I don't think, because any of you would have a time of it in time.

Belle's mood then became the center of attention. Each participant knew her well, having frequently interacted with her in the day hospital unit. There was no doubt that she presented a jovial manner, for each of the support group participants had often similarly commented on Belle's mood, to the point where she came to exemplify for them what the happy, yet functionally impaired, patient can be. In Belle, as in select outside exemplars, participants had a concrete instance of gross impairment who was still, as one of the caregivers noted, "maybe not that bad after all."

As Milt pushed his argument for the real burdens of excessive joviality, another caregiver, Charlotte, whose demented husband, Phil, was perceived as happy-to-lucky, began to reappraise Phil's impairment. Her change of heart turned on what she also took to be the general implausibility of a simple mood-dysfunction argument, considered against particular experiences with her own husband. Charlotte explained.

I'll tell you, Fern, until I started to really hear what Milt was saying, I thought the same. Who could argue with that? Better a happy wanderer than a miserable one. Right? But you know, when I think of my Phil, now he's a happy enough fellow. You know, I don't have to explain. but it can really get to me, too. Like, I know now how it gets to Milt. I mean, just face it, things just aren't that funny. Just because Phil treats everything like it's a joke, it
makes his restlessness twice as difficult. He just can’t get serious about himself and it only makes the wandering worse, just awful sometimes, like he’s laughing at you and kicking you in the behind at the same time.

Neither Fern nor Rose were convinced, responding that they would take Phil any time over their own patients. In support of her view of the composition of impairment, Rose rhetorically and incredulously asked all participants, “You mean to say that someone like that wandering, morose mother in that movie we saw [a popular documentary profile of five Alzheimer’s patients, titled Someone I Once Knew] is not as much a burden as Phil or Belle; you’ve got to be kidding!” Rose argued that the film’s profiled wanderer was “clearly” a case of what anyone hopes to avoid because, as she echoed so many others, “That’s really what I would call a 36-hour burden,” repeating a familiar slogan, also the title of a popular caregiver handbook (Mace and Rabins 1981). For Rose, it was “plain as day,” as she put it, that the movie mother was the worst form of impairment short of being a vegetable. Correcting herself, Rose noted that at least totally demented and bedridden victims stay put.

At this point, one of the facilitators, a respected geriatric nurse, reminded the group of a locally renowned caregiver, Maureen, and her burden. Maureen was not a member of the day hospital’s support group, but she was active in the ADRDA and a familiar figure to all support group participants. Maureen’s renown stemmed from her total devotion to the home care of a husband whom she herself described as, “for all practical purposes, a complete vegetable.” He was bedridden, cognitively blank, and totally lacking in self-care. But she loved him and felt obliged to “stick by him to the end.” The nurse cautioned against being too sanguine about a patient like the bedridden husband, pointing out that, while wanderers were very difficult to contend with, at least they exhibited modicums of awareness, mood variation, and self-control. Then again, the nurse added didactically:

But there’s something to what Rosie just said. The last stages of this disease mean total brain failure and a vegetative existence, if not death. Let’s hope it doesn’t come to that. The bright side is that the total impairment lightens in a way, you know, because the patient stays put. I agree that none of it’s what anybody wants. But I really think that Maureen, in some ways, has less of a burden than someone who’s in that early, wandering stage, don’t you?

From here, it became eminently and frustratingly clear to all support group participants that impairment had at least as many interpretations as exemplars, a common conclusion of many considerations of the matter. It was agreed that what was a nearly total deficit in patient functioning for one caregiver was likely to be perceived much more benignly by others. Moreover, a single patient’s concrete set of dysfunctions seemed to become objectively different burdens depending on what and to whom it was compared, even to different points in the same patient’s earlier functioning or estimated future level of impairment. Support group proceedings showed that there was no guarantee that the apparent facts of impairment of any case would not be transformed, time and again, into lesser or greater objective burdens. Select conditions in particular patient’s total impairment profiles gained or lost the “weight” they were assigned, as it were, with transformations in the interpretation of how each factor generally contributed to the overall burden. In practice, the objective burden could not be billed as an
identifiable entity—a discrete variable—separate from the diverse related experiences that entered into its understanding. Staff interpretations of patient progress and care were likewise organized.

Still, impairment was not simply organized chaos. There were regular agreements and routine conclusions about the objective burden presented by each case. Proceedings showed that there were just as likely to be vehement and studied assertions about the "real" or "true" impairments of a case—its bottom line, as it were—as there were, on other occasions, equally vehement disagreements and dissensions. Whatever was believed to be objective and measurable about the presented burdens of care was just as much about the certainty-status of its deliberations as it was a separate and distinct component of the overall care equation.

FELT BURDEN

Another component of the care equation is the caregiver's response to caring for the disease victim, usually conceived as the strain resulting from the stresses of the burden of care. As with the objective impairment, felt burden is assessed by straightforward inquiries of the caregiver about his or her personal responses, commonly distinguishing the impairment's impact on the quality of the caregiver's daily life from its impact on the caregiver's emotions. A typical quality-of-life question would be whether the patient's impairment made for sleep difficulties for the caregiver or led to the caregiver's social isolation. A common item tapping the impact of the impairment on the caregiver's emotional life would be the degree to which the impairment and caregiving experience was depressing for the caregiver.

Zarit et al. (1980) developed a "burden interview" based on clinical experience with caregivers and on related studies. The interview is a 29-item, self-report inventory, part of an overall assessment battery administered to primary caregivers. Pertaining to the caregiver's feelings and quality of life, the burden interview taps the "discomfort" feature of the 29 items by asking the caregiver to rate each of them for discomfort on a scale from "not at all" to "extremely." As the authors state, "It was assumed that discomfort caused by these situations places burden upon the caregiver," also taken for granted in other studies (p. 651).

Following this, other researchers have developed and administered their own measures of felt burden. Robinson (1983) constructed and validated a caregiver strain index (CSI), a 13-item set of quality-of-life and emotional "difficulties" put into questionnaire format, the respondents of which are asked if the difficulties do or do not apply to themselves. Poulschok's and Deimling's (1984) method was to have caregivers evaluate the burden they felt in response to four separate indicators of impairment. In regard to the patient's ADL impairment, caregivers were required to rate related caregiving tasks for whether the tasks were "tiring, difficult, or upsetting" (p. 233). The felt burden of three aspects of the patient's mental impairment was obtained from caregivers' estimates of whether lack of sociability, disruptive behaviors, and cognitive incapacity, respectively, upset or created a problem for them, on a scale from "not at all" and "somewhat," to "a great deal." Morycz's (1985) independent variable, family burden, was measured by means of a global burden question as well as a family strain scale, parts of a family burden interview. The global question asked respondents to rate, on a
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four-point scale from “not at all” to “a great deal,” whether watching the patient is a strain (p. 338). The family strain scale contained 14 items dealing with subjective burden, which respondents were required to rate in the same way as the global question. As other measures do, the strain scale combined items dealing with quality of life and emotional impact. In the existing studies, the results of various measures are commonly checked against caregiver performance on the Zung Depression Scale (Zung 1965, 1972), a widely applied instrument.

As in other forms of measurement, the measures of felt burden produce numerical descriptions of individual caregiver’s responses to impairment and its caregiving challenges. Moreover, whether or not repeated measures show change, they are assumed to tap the same thing. For example, a change for the worse, from a response indicating a caregiver is not upset by the impairment to a later one showing that he or she is upset, is taken to be about varying degrees of upset, not about entirely different interpretations of the presence or absence of feeling upset.

Data from the field study show that native understandings of the felt burden of care are more complicated. It is evident that caregiver understandings are (1) tied to each other, not individual; (2) assigned meaning against a wide range of circumstances; and (3) not necessarily evaluated in terms of the presence or absence of adversity. We take these up in turn.

Individual Strain?

Although measures of caregiver strain address experience as if strain were individually available for assessment, it is clear from caregivers’ interactions in the support groups studied that strain is a pervasively social undertaking. It is social in the sense that it is interpreted in terms of others’ related experiences, even one’s own as virtually “another’s” feelings against which one’s subsequent considerations are compared. It is an undertaking in the sense that caregivers do not simply exhibit some degree of stress, but concertedly work at understanding their apparently individual responses.

In one of the support groups studied, as in the others, each participant, in turn, described his or her feelings in responding to the increasingly bizarre conduct of their patients. One participant, Sara, reported at length and in considerable detail her husband’s (David) growing irritability and her ensuing quandary at what was happening.

He’s just gotten, let me tell ya, he’s gotten awful. He used to be such a quiet man, always gentle. But not now! He’s a real tyrant sometimes, like a dictator. He orders me around and sometimes he thinks I’m a strange woman in the house. It’s just not like David. My sweet David... It just breaks my heart. I feel so sad and I’m mad at the same time. I start to cry, and then he asks why I’m crying, like my gentle David again. As you can see, it’s very mixed up inside me.

Sara offered a number of incidents to further explain what she faced and how she responded. Each time, she pointed out how confused she was about her husband, how much she loved him and desired to be totally devoted to his care and yet, at the same time, felt he was not the same man she had married and lived with for over 40 years. She noted that there were times when it was obvious to her that he was a very heavy burden, which considerably depressed her; but there were other times, too, when she
firmly believed that her burden was, as she put it, "a labor of love," her personal feelings being righteous devotion of the best kind. It was the latter times that made her feel needed, when she herself appreciated the good she had made on the marriage vows she had taken so many years ago.

As Sara described her feelings, she intermittently turned about face and addressed them herself, as caregivers address each other's feelings and related disease experience. Typically, in soliloquy akin to dialogue, she prefaced her addresses with the phrases, "When I think about myself" and "Looking back over." As an analyst of her own feelings, Sara attempted to discern how she "really" felt about the burdens of care. She wondered, audibly, whether she was just normally "mixed up" or if her quandary was actually a mask for her real feelings, which she might not want to admit to herself. She offered evidence for both alternatives. At one point, she concluded that her confusion was just typical of the common experience in such matters, something to be lived with and through. She even conveyed a momentary analytic triumph that she had discovered what she had felt all along, namely, that she was holding up under it and proving to be a devoted wife after all, a caregiver "till death do us part," which admittedly made her feel very proud. Yet, at another point, she refused to believe that this was normal, but, rather, claimed that she was covering up what she really felt, something dreadfully negative.

As Sara relayed, addressed, and analyzed her feelings, she became interpreter of her own experience, her soliloquy being communicatively identical to the related dialogue between caregivers, which was, like her own, a regular feature of support group proceedings. As an individual analyst of her own feelings, Sara produced a mere variation of what she engaged with others time and again, as did other individuals who similarly addressed and analyzed their feelings. As those present listened to Sara's ruminations—from description to analysis and back—they heard her raise questions and provide answers out of a stock of options they recognized and shared. While in some sense, Sara's feelings and possible strain were obviously her own, it was equally evident they were not idiosyncratic but, rather, held in common—collective representations (Durkheim 1973). In publicly presenting and sorting out her own feelings, Sara did alone what all, including Sara herself, had repeatedly engaged together.

Whether soliloquy or dialogue, each address to, and analysis of, the felt burden of care, ties feelings to a process of interpretation. As measurement thus individualizes strain—being measurement's strain, as it were—every address and analysis serves to collectivize what felt strain is. It was evident in Sara's soliloquy, as it was in others, that what she felt could not be separated from the diverse, somewhat contradictory, ways she and others understood it to be.

Soliloquies regularly became dialogues. As Sara, for example, publicly commiserated about her feelings, she was quickly joined by others. As she herself presented and evaluated her own interpretations of what she felt, now agreeing and now disagreeing with herself, so coparticipants likewise agreed or disagreed, even altering ostensibly firm conclusions. A feeling was never a totally individual possession. As all concerned knew in their own way, individuals' feelings could not simply be discerned (measured) and left at that; they ebbed and flowed with the common experience of which they were an integral part.
Uniformity?

While the structure of individual strain cannot be distinguished from its social organization, its substance is socially distributed. Time and again, participants in the support groups studied mentioned that their feelings about the burden of care depended on the circumstances in which they are considered. Not being cross-situationally uniform, the accurate assessment of feelings during measurement did not warrant what they would be on other occasions.

The issue of uniformity is not the same as constancy. Should feelings remain the same from one measure to another, the constancy would be detected by sensitive instruments, as would actual differences. Uniformity, in contrast, pertains to situational variability, measurement itself being a situation. It is evident that caregivers take situations into account in assessing what and how they feel.

The test items and tasks of the day hospital’s research program were, if not identical to those used in existing studies of impairment, burden, and institutionalization, considerably overlapping with the studies in form and content. While caregivers were administered the items and batteries both individually and as a group, they were nonetheless told, in either case, to answer as accurately as possible and to answer for themselves when questions dealt with their own feelings. Ideally, as such measurement commonly assumes, respondents were to virtually reach into their store of feelings regarding varied facets of the burden of care, evaluate the status of those feelings, and report them accurately.

Yet, a number of comments and questions from the caregivers, expressed during the measurement of their related feelings, shows that the issue of uniformity was repeatedly raised in response to test and questionnaire items. Completing a “burden interview” consisting of 20 items drawn from Zarit’s et al. (1980) 29-item, self-report inventory of the same name, select caregivers would periodically ask the test administrator the meaning of particular items. For example, wondering how to answer the item “Do you feel strained in your interactions with your spouse/parent?” Mildred, whose husband was an Alzheimer’s victim, raised her hand and asked:

I was just wondering what to do with number 12. This question about my strain... I’m not sure what you mean. It all depends, you know. When I’m in the thick of things and John’s [her husband] acting up when I’m trying to get him dressed, now that’s strain. But when I think about some of the things that happen sometimes, it’s a good laugh, like the time John tried to dress himself and came into the living room with my panties on over his pajama bottoms! Was that a scream. I nearly split a gut. What a joke! I needed that. I laughed all day. Even when he started to act up when I tried to get him to take them off, I joked with him about it.

Mildred’s earnest question and comments indicated that, in her experience, the meaning of strain shifted substantively. If she chose to answer the burden interview item in terms of John’s acting up at the time he was being dressed, the acting up literally predefined strain, acting up being a form of strain. If Mildred chose to answer the item in terms of humor-bound acting up—how funny he can be at times—the funny framing would serve to define the acting up as part of a joke; jokes not being stressful but, rather, a source of relief from stress.
Questions raised by one caregiver and overheard by another sometimes suggested options not formerly considered to be a way of interpreting an item. For example, when Harold, whose mother was the patient, asked if it was acceptable to answer an item about his felt embarrassment over his mother’s behavior in terms of how the mother acted in front of guests, another caregiver, George, reconsidered his own earlier response to the same item. George raised his hand and told the test administrator that he had already answered that question “not at all” because he had gotten used to his wife’s, the patient’s, behavior and was not embarrassed by it. Having overheard Harold’s question, however, George suggested that he might be embarrassed in front of guests, too, and asked whether he should go back and change his response.

Social distribution even extended to interitem circumstantiality. Successive items circumscribed the meaning of previous items, to which some caregivers said they returned and either did change or desired to, as they proceeded through the test. Individual test and questionnaire items were not so much independent as they were mutual catalysts of persons’ dialogues with their own related experiences, returning us to the pervasive sociality of individual responses.

The social distribution of strain, of course, was not just evidenced in test situations. The broad substance of support group proceedings could be described, overall, as a study in emotional nonuniformity. Certainly, over time, participation in support groups served to change, by degrees, caregivers’ interpretations of their felt burden. Repeated measurement indicated the extent to which such change had or had not taken place. Yet, it was evident, too, that the change was not uniformly a matter of varied degrees of both experiential continuity and discontinuity. It was not unusual for a caregiver to feel rather depressed by the current and prospective burdens of a patient’s growing impairment, at one point in time, and to express feeling rather fortunate and “not so bad after all” in comparison to the “really depressing” picture facing another caregiver, at another point. Accordingly, support group proceedings served to transform the emotional meaning of the “same” burden for caregivers from one thing to another, abrogating uniformity.

Negativity?

If not explicit, it is nonetheless taken for granted in existing studies that the care equation pertains to adversities. Impairments, burdens, stress, strain—the language expresses negativity. Although it is obvious that caregivers experience considerable suffering themselves as a result of their victims’ ordeal, making caregivers Alzheimer’s disease’s “second victims,” a familiar enough phrase, field data show that caregivers’ interpretation of their situation is not always negative.

The testimony and responses of individual caregivers indicate that there are occasions when caregivers do not conceive of strain as a natural byproduct of stress. It is not a matter of more or less strain resulting from stress, but an entirely different sense of caregiving. As if to teach a lesson, Nancy, a locally renowned, long-time, and devoted caregiver, put it this way in regard to what she perceived as the unnecessary connection being made between patient and caregiver:

I’d like to say something. You’ve all been pretty hard on yourselves and I really think that maybe you’ve got it all wrong. “Burden here, burden there.” That’s all I hear anymore. By God, it’s a loved one! It doesn’t have to be a burden, does it? For me, I can truly say that it’s
a challenge, yes, but I accept it like it's a family matter, a duty. And you just do for family. And, to tell you the real truth, I've been very pleased to be able to do it for him [her husband, the patient]. He's all there is for me and I'm happy to care for him. It makes you kind of proud-like to be able to say you can do it. It's our responsibility, you see. Actually, it's not a matter of my good or your bad feelings at all. Think about it.

What Nancy suggested was not unique. Support group proceedings showed that at least two images of the personal side of the caregiving experience underpinned participants' offerings and exchanges. One image was the version that informs existing studies of the burden of care, the common interpretation of the care equation, a more or less negative series of covariations. Another image was strikingly different. In this version, what the patient presented was not so much a burden but a challenge, for some, part of the wide range of lesser or greater challenges of human experience. As such, the orientation to the challenge was not one of personal tribulation but of successful confrontation and eventual triumph. Caregiving was something to behold, to be proud of, a sign of effective human stewardship. Success and effectiveness were not simply a less-negative outcome of the care equation as commonly understood; rather, they were realizations of an entirely different sense of human straits and obligation.

The two images did not neatly categorize caregivers into separate and distinct types, for some caregivers, at times, spoke of and interpreted their feelings in tune with one image and, at other times, echoed the other image in assigning meaning to their experience. The images, then, entered into their lives as tacit structures for representing what was otherwise meaningless (cf. Gubrium and Buckholdt 1982). It was not uncommon for disagreements or deliberations in support group proceedings to bring the images to a proverbial head, as participants now presented cases and evidence for one version of the caregiving experience or the other and now transformed their understanding of their experience into the other version. Indeed, a good share of the controversy between participants in support groups turned on the mutual credibility of image and experience as appropriate understandings of the personal meaning of impairment and caring. In use, the images cast considerable doubt on simple negativity, again delimiting measurement.

**INSTITUTIONALIZATION**

The third component of the care equation is the decision of whether to continue home care or to seek institutionalization, typically a nursing home. Except for the consideration of the effect of social support, existing studies have approached the decision as circumscribed by the degree of impairment and the felt burden of care. Zarit et al. (1980, p. 649) state that because home care entails great psychological, physical, and financial costs, institutionalization is a likely source of relief. Morycz's (1985, p. 347) path model for predicting caregiver desire to institutionalize patients points to caregiver strain (burden or felt stress) as the best predictor; the greatest strain experienced when caregivers have little social support available to them. All in all, the relationship between components of the care equation is treated as a rational calculas, where, by and large, one thing leads to another. Increasing impairment leads to growing feelings of strain among unassisted caregivers and, finally, to eventual institutionalization (Lynott 1983). Or at the very least, as Zarit et al. (1986) have recently suggested, while
the patient's symptoms may not directly predict nursing-home placement, the caregiver's feelings of burden are associated with institutionalization.

Again, field data show that the experiential relationship of impairment and strain, as it figures in the decision to institutionalize, is more complicated. It is not so much that the reference to three component variables misrepresent caregivers' experiences, as that the variables are considerations within a larger sense-making and evaluation process.

The decision to institutionalize commonly is centered on the question of when "it's time." The expression signals the decision in a variety of sources, from ADRDA chapter newsletters to caregiver handbooks and support groups proceedings. Advice columns, even folk poems contributed to newsletters by caregivers, offer virtual recipes for deciding when it's time to "let go" and seek a nursing-home placement. For example, a poem, itself titled "It's Time," written by Dorothy Hessel of the Detroit chapter and reprinted in a number of newsletters, lists the conditions indicating institutionalization. Following the initial question, "When should I give up my loved one to another's care?" among the conditions cited are:

- When he [patient] sits in front of me and objects when I talk on the phone.
- When he doesn't remember to use the bathroom.
- When he gets out of bed and runs into the night.
- When he thinks people are "after him."
- When he runs away and I am GLAD to have a few minutes to myself.
- When I DO fall asleep and I am too tired to respond to his needs.
- When I feel I might die first.
  Yes! It's time!

While these and other maxims contained in that portion of the growing public culture of the disease pertaining to institutionalization suggest that timing is a straightforward process of matching patient conditions against caregiving capabilities, the process is socially organized. Being a regular concern of support group participants, the expression "it's time" is routinely heard in the sharing of caregiving experiences. For example, following an exchange of stories about the "really bad things" that have occurred of late, a common interjection might be, as one caregiving wife put it, "Yes, you know it's time when they start to piddle on the floor!" Yet such assertions do not automatically signal a decision to institutionalize, for timing and such undesirable conditions as piddling are interpreted, weighed, and reinterpreted against ongoing considerations of other components of the care equation, say, in terms of the meaning of piddling as an impairment and felt burden.

A series of discussions in one of the support groups studied, centering on a wife's apprehension over her husband's, the patient's, increasingly careless toilet habits, shows
how the question of institutionalization (usually taken in existing studies to be the effect to be explained) actually works back onto its ostensibly precipitating conditions, onto impairment and felt burden. For two weeks, participants had been sharing what one of the facilitators had called “horror stories” about patient conduct, such as tales of midnight wanderings in subzero temperatures and violent outbursts in public places. Indeed, amidst a moment of rather vivid disgust, one of the caregivers asserted that the group had gotten very morbid of late and that it was becoming quite depressing to her. At one point, after a patient’s daughter, Carol, reported how dismayed she had been to find that her mother had mostly missed the toilet when the mother last defecated, another participant, Vel, whose husband had Alzheimer’s, flatly stated:

Look, when I hear those things, I think if it comes to that, that’s it! No way will I put up with that kind of thing. I love Ben dearly but I couldn’t handle that. I’d really have to find a place for him. I hate to say it but that’s when I’d say, “It’s time.”

Yet Carol’s response suggested that condition and decision were not simply linked. Carol remarked that institutionalization had, indeed, crossed her mind as she cleaned her mother and the soiled bathroom, but, then, she added:

I thought, too, well it really wasn’t her [the mother’s] fault. She didn’t mean it. It was an accident. And we all have accidents, don’t we? Even the dog sometimes makes a mistake right there on my carpet and I wouldn’t dream of putting him away. Sure, at the time, I thought this was the worst thing that could happen. But, later, you change your mind. She could have wandered off and gotten hit by a car. But, thank heavens, she didn’t. [Carol knocks on wood.]

Carol talked at length about the incident, what it had meant to her then and how its meaning had changed over time. The incident represented a different degree of impairment as Carol considered her mother’s related intentions and compared what the mother had done with what other impairments her mother and other patients, even family pets, presented. It was evident that the decisive impairment and felt burden were matters of continuing interpretation.

Some time later even Vel reported a similar incident, one that she had vowed earlier to be the deciding criterion for institutionalizing her husband, Ben. As participants are wont to do, Vel introduced the incident by stating that she wanted to share with the group something that had just happened and that was troubling her. She relayed, tearfully, how she and her husband had been spending a very nice evening at home together watching a favorite television program. During one of the ads, Ben had gotten up to use the bathroom, which was not unusual. A few minutes after he returned and sat down again, she smelled a putrid odor and, at first, assured herself that it was simply drifting from the bathroom. But she soon guessed that “the worst” had happened. Checking her husband, indeed it had. He was sitting in it, seemingly unfazed. Choking on her words as she reported what happened, Vel concluded:

It was the most frightening thing for me. It was the worst thing he could have done, really. I’ve been very, very upset. . . . Excuse me. I need to talk about it. Ben’s all I’ve got and I don’t know what I’d do without him. But this kind of stuff. . . . He’s a wanderer—you all know that—but I can handle that. But this?
The group discussed the occurrence. Select participants reported similar incidents and feelings, some of them familiar to the group and repeated as illustrative of a common experience. As others did, Carol reminded the group of her own experience with her mother, who, since then, had had other similar accidents. Yet Carol added that, while institutionalization had and still does occur to her, it had never been linked as closely in her mind with toilet habits as it seems to have been for Vel. As the discussion unfolded, it was evident that there were several different interpretations of the decisive condition. Indeed, one of the participants stated flatly that all the soiling and wandering in the world did not matter as much to him as that his wife continued to recognize that he was her husband and appreciated, in her own way, what she meant to him.

What was clear in this and other support groups was that, while standard recipes for when "it's time" were common features of caregiving discourse, regularized through repeated discussion, the recipes were interpreted against individual particulars. While all agreed, for example, that it was time to institutionalize the patient when the impairment got completely out of hand, what the latter meant varied from one caregiver to another, and between caregiver considerations. The variation was subject to experiential comparisons, as were other components of the care equation. Vel, herself, engaged the same processes as she considered and evaluated the decisiveness of Ben's toilet habits against others' testimony, now convinced that something had to be done and now equally convinced that, perhaps, it was not as bad as other conditions of impairment could be.

While some have said that the financial costs of institutionalization, such as the required spend-down provision to qualify for some forms of assistance, are the considerations of last resort, again the data suggest otherwise. It is evident that financial cost—for some, of financial ruin—are weighed against other costs, such as the loss of companionship, the breech of dedicated obligation, the shame of giving up, even the denial of one's love for the patient. Such comparisons are part of the continuing interpretation of burden. As Lynott (1983) pointed out, even actual institutionalization does not end the process. Former caregivers continue to compare and contrast, learn new decisive conditions, and relearn what went, or should have gone, into their very own decision that it was time. This serves to define and redefine what the "cost" of the decision really was, continually altering the experiential quality of the linkage between institutionalization, impairment, and strain.

CONCLUSION

We have used the term *equation* to highlight an important difference. A comparison of caregiving as conceptualized in existing studies with the field data has shown that a concept of equation, implicit in the studies, stands in considerable tension with the notion of experience. Equation signifies a calculus of components. As components, impairment, felt burden, and the institutionalization decision are independently discernible, each, in its own right, representable by measurement. As parts of an equation, the results are subject to the logic of covariation and regression, providing a metrical understanding of their relationship.

But as concrete categories and concerns of experience, we have seen that what might, at first blush, be a component, such as impairment, loses its empirical indepen-
dence in practice. The related caregiving experiences of all concerned—patients, family members, facilitators, service providers—show that the meaning of each ostensibly distinct component is as much a continuing matter of definition and interpretation as it is understood to be an objective entity. Each takes on its experiential meaning as it is assigned a place in relation to other considerations, in and about caregivers' concerns. The covariation of components, if it can be addressed in that fashion at all, is an emergent and practical set of qualitative transformations, embedded in a growing culture of understandings of their separate and collective meaning.

If we are to permit the Alzheimer's disease experience, especially as it centers on the burden of care, to reveal its native realities and understandings to us, we must be willing to ask how measurement infringes on them. This is not a question of inaccuracy or instrumental crudeness: rather it concerns how we shall proceed to look at and think about what is so plainly part of the experience. It pivots on two options: (1) allowing the transformational and reflexive qualities of experience to overshadow measurement, the latter of which is, from an experiential point of view, an inappropriate calculas or (2) imposing stricter measurement criteria on the care experience and thereby reaping concise, yet unrepresentative, depictions.

The field data we have brought to bear on the care equation suggest that we reconsider measurement as a means of understanding caregiving, that we, instead, permit ourselves to discern its nonmetrical logic. This we can do by attending to the practical constructions and transformations of the meaning of impairment, strain, and decision making, as they are taken up by those whose experience they categorize, calling for a qualitative methodology (see Ory, Williams, Emr, Lebowitz, Rabins, Salloway, Sluss-Radbaugh, Wolff, and Zarit 1985, p. 638). What the study of caregiving now needs is a new language, the analytic services of interpretation, transformation, and circumsitualty. Without them, measurement will take us farther away from the object of our concern than we ever intended. What is more, without them, intervention, even though rationally planned and concisely programmed, will service nothing but accountability.

REFERENCES


