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Incommunicables and poetic documentation in the Alzheimer's disease experience

JABER F. GUBRIUM

The publication of Thomas and Znaniecki's (1918-1929) monumental study, *The Polish Peasant in Europe and America*, established the personal account as an important source of social scientific data. The use of letters to document the social and personal sides of experience was followed by the analysis of other forms: autobiographies, diaries, guerrilla journalism, oral history, photographs, film (see Plummer 1983). It seemed that personal documents lent themselves to detailed description of the flowing complexities of everyday life — the rationalities and rationalizations, the retrospections, visions and revisions, reconsiderations, contradictions, the fitful shifts in meaning and intention.

While personal documents serve sociological depiction, respondents occasionally suggest that they are, as text or testimony, too prosaic to convey the greatest depths of experience. The common opinion that certain experiences cannot be put into words or cannot be described informs us that other communicative means are needed and that, if found and applied, such means convey what plain words cannot. At the same time, we have long thought that certain forms of communication — music, the visual arts, poetry — are able to penetrate the depths. Yet there has been an understandable reluctance in the social sciences to entertain these forms as personal documents — in part because they are associated with the arts, not science, and in part because what they document is believed to be incomprehensible.

This paper attempts to bridge the gap by taking folk poetry as a native means of documenting that which, by its presumed nature, cannot be conveyed discursively. In and about the world of those dealing with Alzheimer's disease (senile dementia), many poems have been written and/or distributed. Their usage provides a vivid case study of evidence for a non-substantive communicative function. Following a brief medical description of the disease and its communicative burden, three aspects of poetic documentation in folk application are considered here: (1) usage as

a route to the incommunicable, (2) types of incommunicable, and (3) the structure of poetic documentation.

The disease's communicative burden

Alzheimer's disease is a common affliction of later life that affects the brain cells. According to a recent government progress report (U.S. Public Health Service 1984: 1), it is the cause of disorientation, confusion, and forgetfulness in approximately two million elderly Americans, and is the primary reason for their institutionalization. Until recently, it was thought that Alzheimer's disease afflicted only those under 65; it is now recognized as the most prevalent source of severe intellectual impairment in older persons.

The disease's inexorable progress is manifested by diverse symptoms. The onset frequently goes unnoticed and may be defined as emotional upset or physical illness. Gradually, the Alzheimer's patient becomes more forgetful, especially about recent events. He may neglect responsibilities in ways that could endanger his life, like forgetting to turn off a gas stove. As the disease progresses, memory loss increases along with other behavioral changes such as confusion, restlessness, and agitation. The patient 'wanders', walking about aimlessly, not knowing where to return. At worst, total disorientation occurs; cognitive deficiency is such that even the most familiar faces become strange and personal care disintegrates into lack of control over bodily functions.

Whether Alzheimer's disease is advanced old age or aging's pathological end-point (see Behnke, Finch, and Moment 1978; Tomlinson, Blessed, and Roth 1968, 1970; Johnson 1985; Gubrium 1986a), it is clear that the results are devastating for both the afflicted and their caregivers. The increasingly familiar slogans of the Alzheimer's disease movement, centered on the Alzheimer's Disease and Related Disorders Association (ADRDA), signal the devastation, The 'disease of the century' is said to be a 'silent epidemic' that 'steals bright minds', to be like a 'living death', or a 'funeral that never ends', presenting a nightmarish '36-hour day' burden to those who care for the victim. The pain of mental demise, the growing loss of recognition, the lingering presence of a loved one who is 'no longer there', yet physically fit, all present an indescribable experience, according to those concerned. As is commonly remarked, it is 'dying without death'. Still, as apt as that phrase may be, it is not believed to fathom the wrenching depth of the experience.

The desire to make sense of what is happening to a loved one and to share the experience as a means of coming to terms with it place a

considerable descriptive and communicative burden on those concerned, both patients and caregivers. As caregivers repeatedly note, 'It's just so hard to put into words what it feels like'. It is not that those concerned are at a loss for how to describe disease matters like symptoms, onset, progress, prognosis, diagnosis, treatment, patient management, caregiver support, the process of adjustment, financial burdens, and the decision to institutionalize; the many facets of the disease experience are documented in a growing body of lay and professional literature. It is portrayed in videotapes, in film, and in the broadcast media. Indeed, it can be said that, descriptively, the disease's documentation exists in a recognizable public culture (see Gubrium 1986a), where it is now being suggested that Alzheimer's may no longer be a silent epidemic. Rather, the communicative burden regularly referenced by those concerned is nonsubstantive. According to a caregiver, '[It's] a mysterious something about it that tells it all'. The burden and sentiment press for experiential documentation different from concise description. Accordingly, as far as communication is concerned, disease matters were found to fall into two categories: substantive and incomprehensible.

The incommunicable and poetic usage

As part of a field study of the descriptive organization of senility (Gubrium and Lynott 1985; Gubrium 1986a and b, 1987), many instances of the disease's communicative burden were observed, each urging those concerned to find means of conveying the incommunicable. The ADRDA, a national network of over 100 chapters, sponsors support groups for caregivers in every major city in the United States. Participant observation in support groups in two cities showed that a regular concern was how to convey both the patient's and the caregiver's side of the disease experience, 'beyond what everyone already knows', as one caregiver put it. Related fieldwork in a small day hospital for Alzheimer's disease patients that offered a regularly scheduled support group for the primary caregivers — mostly spouses or adult children — also offered evidence of the need to communicate the depths of the experience. Content analysis of the disease's lay literature — caregiver handbooks, informative brochures, chapter newsletters — revealed the same urgency.

References to the incommunicable are not idiosyncratic. Field data shows that it is acknowledged by all concerned, from patients and caregivers to professionals. For example, it would not be unusual for a participant in a support group for caregivers, who had tried mightily to inform co-participants of what it felt like to see her husband gradually slip

away from her, to give up trying and conclude, 'Oh I just can't describe how it felt'. Yet the typical response to this indicates that, despite the acknowledged lack of precise substantive communication, there is nonetheless something — real, concrete, yet ineffable — to be conveyed, something which is paradoxically incommunicable. A remark such as 'Yeah, we know what you mean. It's there but you just can't describe it' signals acknowledgment and consensus regarding the unknown reality being referenced.

Professionals too accord credence to the incommunicable. For example, on one occasion a well-informed nurse who was an active member of the ADRDA spoke at length to an audience of other nurses, physicians, and caregivers about the disease and its care burden. In her conclusion, the presenting nurse paused briefly and stated:

As you know, like anything else, there are some things that you just can't put into words. Those of you here who've experienced it know what I mean. So pardon me if I can't tell it all but you know what I mean.

There were several nods in the audience, and even a friendly interjection by the spouse of a locally renowned Alzheimer's disease victim who asserted, 'Right on, it sure is real enough anyway ... and you sure as heck *can't* put it into words!'

As far as reference to the depths of experience is concerned, respondents did what is otherwise culturally commonplace, though perhaps with a greater sense of urgency. In that regard, they were not different, communicatively, from others likewise concerned. Still, there were situations where the incommunicable, admittedly not conveyable, was indeed relayed, though not substantively. Here respondents' practice of using poetry to communicate and to document experience more nearly resembled a literary counterpart than it did the culturally commonplace. The use of poems to actually convey the incommunicable, though, was not as prevalent as the acknowledgment of the incomprehensible depth of experience.

The documentation under consideration centers on *folk* poetry, informally written by and for those whose experience it is meant to communicate. All concerned are encouraged to contribute. For example, reprinted on the back cover of the May 1985 issue of the Duke ADRDA newsletter is a four-line poem taken from the January 1985 issue of the Columbus, Ohio chapter. Immediately following the poem, in bold type, is this message:

Call For Original Works

Many of you have written poems, stories, 'cartoons', etc. Please share them with us for 'The Caregiver' newsletter. We want to *hear* from you!

Thirty-two folk poems were collected and analyzed, including virtual classics such as the poem entitled 'Heart's Memories', presented as if written by an Alzheimer's disease patient for loved ones, and one entitled 'My Joe', which conveys the emotional agony of a loving wife witnessing the inscrutable mental demise of her husband. Some poems, about life's hopes and despairs in general, have been adapted to the Alzheimer's experience by inclusion; appearing on newsletter pages or used in related oral presentations to share what words cannot, the poems are understood to apply to the disease in particular.

Most of the poems are written by a caregiver, usually a spouse. Some are composed by the caregiver for the patient; in others the writer, posing as the patient, documents what mental demise must be like. A few are said to be written by patients themselves. There are also poems written by young children about their experiences with increasingly demented grandparents, meant to convey the child's sense of the mental loss of a cherished elder. Some poems about volunteers and support groups offer messages about the unspeakable depths of devoted giving and sharing.

Consider the well-informed nurse (introduced earlier) on another occasion, this time speaking to a class of gerontology students. Recognizable topics were addressed — among them symptoms, course of progress, and possible causes. The structure, history, and contributions of the ADRDA were also discussed. Students learned in substance about the disease experience from all sides — the impairment and the burden it presents to caregivers, and what is being done about both. Having finished, the nurse asked for questions, whereupon several students requested clarifications of particular details and further information about concerns only briefly mentioned. When the final question had been answered, the nurse commented on what she perceived as frustration:

Gee, there are so many questions, aren't there, when you think about it? I was just thinking how frustrating it must be to hear all of this and not really know how terrible and heartrending it all is. You couldn't imagine what it's like for these folks. It tears me apart to see what they're going through. Let me end with this. I think it says what I couldn't even begin to tell you. It's a poem that was written by a caregiver about what she's going through and I think it says it all.

She then read the poem to the class. When she had finished, her final comment was, 'There! Now, doesn't that kinda tell ya what it's like, right from the heart'. She gently tapped her chest.

The substance of the poem was rather similar to what the nurse had previously informed the class in prose. Like her lecture, the poem's content dealt with mental disease, lost personhood, medical futility, and

the desperate concern of loved ones. In fact, substantively, the poem related sparingly what the nurse had more fully but prosaically described in her talk; point for point, the prose was more informative than the poetry. Moreover, the poem was quite poorly composed as compared with the lecture proper; the poem was ungrammatical and rather gushy.

Yet despite its comparatively poor substantive quality, the poem was said to convey something — deep and significant — which, according to the nurse, she had not managed to communicate earlier. Whatever that was, having completed the reading, she felt satisfied that she had, by means of the reading, said it all. She claimed to have communicated the incommunicable.

Just as references to the depths of experience are commonplace, the nurse's poetic usage was not an isolated incident. In and about support group proceedings, communicative urgencies could serve to bridge the gap between substantive and incomprehensible matters. For example, on one occasion several caregivers in one of the support groups studied had been attempting to report what the patient, as one caregiver put it, 'must really be going through down deep inside'. They all had difficulty, even though it was apparent that each had already described the sum and substance of their concern in considerable detail. Yet something was said to be missing. Then, quickly, a caregiving wife drew a poem from her purse and read it aloud. It was about the patient's feelings, but substantively it was a poor facsimile of what had already been said in greater detail. Nonetheless, when the reading concluded, the wife and her audience all agreed that the poem said it all — what none of them, until then, had been able to put into words.

Lay literature also shows evidence of poetic usage. The most telling instances are contained in the numerous newsletters published by various ADRDA chapters. Monthly or quarterly, four to ten pages of disease-related news are distributed from local chapter offices: caregiving tips, personal profiles of caregiver experiences, fundraising efforts, so-called medical breakthroughs, support group activities, news from national headquarters in Chicago, memorial listings, ads for 'how to' books, tips on legal and financial planning, and more and more often, poems about the disease experience. All material is freely exchanged by the chapters and regularly reprinted, part of the common effort to share and spread the word. A poem found for the first time in a chapter newsletter is likely soon to appear in others.

Again, a point-for-point comparison of the substance of the poems with adjacent newsletter articles dealing with similar matters shows that as far as content is concerned, the articles are more informative. Yet, as in verbal communication, it is also evident that their juxtaposed messages to readers are not the same; this is suggested by the occasional brief explanatory

comments on the poetic messages. For example, the November 1982 issue of the Duke ADRDA chapter's newsletter contains a poem that deals with the sharing of caregiving experiences. The poem follows an article entitled 'Am I my brother's keeper?' The article explains how one caregiver arrived at a decision to institutionalize her severely demented husband. She describes her subsequent guilt at having placed him in a nursing home, reporting how she attempted — by means of humor, an objective outlook, and frequent visitation — to contain the feeling. Gradually, with others' support, she came to terms with her decision, realizing that she could not have continued to care for her husband at home. Finally, the article states that its author, the caregiver, does not intend to sever her relationship with support groups when her husband dies and the caregiving burden ends. Still, despite the article's relatively detailed documentation of the successful path that others' support allowed her to follow, the author needs to say more about the devoted help, something which plain words cannot convey. The last sentence of the article reads: 'There is a poem I would like to share with you which, I believe, says it all — what a support group should be all about'. The poem follows. It is allegorical and is meant to communicate, by means of a poetic depiction of an elderly voyager's good works on behalf of other pilgrims, what the indescribable course of caring and support is like.

Types of incommunicable

Two types of incommunicable are distinguished, divided in accordance with the 'two victims' theme of the disease movement: the incommunicable depths of the demented victim's experience on the one hand, and the unfathomable depths of caregiving — characterized as the devoted '36-hour day' that virtually becomes the lived life of the patient — on the other. Both victims suffer from the 'funeral that never ends' — unspeakably so. The types are categorically signalled by special terms — respectively, the heart and soul of mind and the love, hope, and faith of those concerned. While the special terms, like other terms, convey particular information in their own right — in this case, about substantive feelings — they are special because they are also taken in general to reference the indescribable depths of both the cognitive and the emotional.

The heart and soul of mind

It is said that for those actually afflicted, the disease steals once bright minds. Insidiously, sometimes slowly, yet inexorably, the mind is por-

trayed as slipping away as the patient becomes speechless or otherwise unintelligible. Many related questions are posed by those concerned. Does this mean that, physical fitness aside, the person within has actually died? Does it imply that bereavement is in order, that one ought to close off one's affairs with someone who is now, as a slogan claims, 'the shell of a former self'? Might not the person, once loved, still be there in heart and spirit, behind the 'shroud of silence' (another slogan), aching for human contact but unable to reach out? Answers settle on what is made of the relationship between communicables and the incommunicable — respectively, between mind and body on the one hand, and heart or soul on the other (Gubrium 1986b).

Body and mind as intact entities are assumed to be denotable. By the same token, their demise is considered demonstrable — the poetry tells us as much. At the same time, the poetry dwells on the ineffable: on the patient's love and on the heart and soul of mind, which may linger on forever. For example, the poem entitled 'Heart's memories', written by a caregiver (Louise M. Eder) from the patient's point of view, expresses for the patient what no one can communicate — the living domain behind mind and body. Heart and heart's memories present the essence of mind, known only through faith and love, the latter essentially incomprehensible. Taken from the Spring 1984 issue of the Kansas City chapter's newsletter, extracts from the poem follow:

I remember you with my heart
 My mind won't say your name
 I can't recall where I knew you
 Who you were
 Or who I was.

But I do know you
 I know I knew you
 And I do love you
 I know how you made me feel
 I remember the feeling we had
 together.
 My heart remembers
 It cries out in loneliness for you
 For the feeling you give me now.

I can still feel you
 I can remember you with my heart
 And a heart memory is maybe
 The most important memory of all.

In a similar vein, Joy Glenner of the San Diego chapter explained in the December 1983 issue of its newsletter, 'I felt like speaking for the patient after hearing one family member relate her irritation at having to handle her who has AD [Alzheimer's disease]. There was no feeling, sympathy, or empathy'. Extracts follow from Glenner's poem, which appeared in the same issue.

Dear Family and Friends:

Please try to understand
What I am now, not think of me
As I was.
I am alone, shut in
With my fears
My frustrations,
My forgetfulness.

Be patient, for
I do love you,
And I need your help and love
So very, very much.

Your Alzheimer Patient

It is believed that the poems provide a glimpse of facets of experience which no words can express: the heart and love of the patient. It is not just memories that are recalled; it is their indescribable core — *heart* memories, said to be the most important of all. Even while the victim's mind has failed, he nonetheless can express all its functions — but, ironically, in the silent voice of the incommunicable, the deep speech of feeling, not the plain categories of emotion, which can be described readily enough.

Matters of heart are as broad as those of mind: where one remembers, one can also long; where there is sincerity, one's conduct can also be heartfelt. As rich and extensive as the expressions of mind, the life of the heart or spirit is nonetheless not discursively articulatable, but merely capable of being referenced.

Other poems attempt to describe the spiritual distillate of mental demise, whose sustenance still requires love, being an underlying presence to be cherished. This is conveyed in a poem entitled 'Alzheimer's shadow', by Ellen Snavely, who wrote it for a close friend whose mother had Alzheimer's disease. Extracts follow from the October–November 1984 issue of the Des Moines chapter's newsletter:

My mother took passage one day
To travel to a strange and alien place

How I wish I understood more clearly
 Her acts preceding the slow and lonely journey
 Had I laid a crimson rose on her small casket
 Or scattered her ashes over her beloved garden
 Warm, healing tears would surely have washed my sorrow
 But there *was* no satin-lined casket
 No ashes to rest on lilac, lilies, basil or thyme,
 For my mother left me her shadow.
 Frail, tortured, strange but yet a
 Living, breathing, *needing* shadow.
 In torment I turn away from this small ghost
 To bid a loving farewell to my real mother.
 The mother who gave me life
 And taught me to live and love and laugh
 Now my storm of wild weeping is ended.
 I seek out the strange small shadow.
 I smooth the thin white hair and whisper,
 'Don't be afraid. I will learn to cherish and care for you'.
 I hold her close in my strong, young arms.

'Alzheimer's shadow' tells us a great deal about the relationship understood to exist between body, mind, and soul as objects of experience. It is evident in the poem that it is not body that has died, but mind; what remains is a shadow. But shadow is clearly a metaphor for something unspeakable yet referential. The daughter not only smooths the thin white hair, she whispers something, too. She speaks to the uncomprehending, to something that admittedly is no longer there. Evidently, though, whatever it is is there for the daughter. And that being-there-for-the-daughter stems from the daughter's faith that it is 'her', the mother, not a mere body, whom the daughter holds in her strong arms. While mind is gone, what remains as a mere shadow of a former self is the-entity-remembered, once so implicitly (but always ineffably) assigned to the body being held. That object, the-mother-remembered-by-the-daughter, is what the daughter communicates to us by means of the poem, the heart of mind.

The shadow's status as a thing, as the object of description, is bound to its assignment, a hyphenated (social) objectivity, as it were (Gubrium 1986b). It is nonexistent apart from the daughter's (or another's) intention since, admittedly, the mother is no longer there save the 'small ghost' she is — which itself is a familiar member of that class of terms that signal the incommunicable, allowing one to communicate about them. While the small ghost is an empty category, it is still categorical, and as such is communicable. The recognition that it is a poetic documentation and not

a mere word (or fiction) conveys the reality of heart and soul, making it possible for ghosts and shadows among hearts and souls to be understood as livingly, lovingly, among us.

Experiential objects are hyphenated to emphasize that they are understandings as much as they are things (cf. Lacan 1977: 42-64). The heart, soul, ghost, and shadow, not being 'there', nevertheless return to the caregiver, and to all concerned, by means of their special signifiers. As the poem presents them and they are received, the incommunicable is acknowledged. In 'Alzheimer's shadow', the body saves — fixes — the soul, if not the mind. The body, that which the daughter concretely holds, merely locates the object of her whisper. So we are told implicitly that all the concrete realities both remembered and present point to, support, and yet are not the thing, the shadow, so poignantly being held 'close in my strong, young arms' — mother-for-daughter.

Love, hope, and faith

It is not only matters of heart and soul that cannot be put into words; neither can love nor selfless devotion to the past and living presence of the person behind the disease. A number of poems concern the depths of loss and devotion, conveying what is said it 'really' means to remember and care, again 'saying it all'.

The poem 'My Joe', by Virginia Burns, is among those most widely reprinted in newsletters. It communicates the mystery of loss. The poem repeatedly asks 'why?', but never articulates the mystery lurking behind it. The question is about lost love, the desire to know how love torn asunder can be explained. The following extracts are taken from the Summer 1983 issue of the Kansas City newsletter.

There are so many things
That I would like to know
Why him, O God, Why
Please not my Joe.

His mind's so bright and clear
He's charming and he's witty
He's all that I hold dear
He tells me that I'm pretty.

But now he sits and stares
Not seeing anything
He never speaks at all
He can no longer sing.

I miss him so you see
 Although he's still around
 He no longer knows me
 His judgment isn't sound.

Alzheimer's they tell me
 He will surely die
 Silently I listen
 And then begin to cry.

There are so many things
 That I would like to know
 Why him, O God, Why
 Please not my Joe.

While those concerned speak of hope, time and again they also find that what they hope for is challenged by the reminder that there is no cure, and that there is not likely to be one for years to come — if ever, some say, for in a certain connection Alzheimer's disease is aging. Yet death — ending, nothingness — is said to be incomprehensible against what one remembers and still firmly knows and thinks of another. Belief in the living presence of the person behind the disease, against its simultaneous opposite — absence or death — is inconceivable. Incomprehensibly figuring in a mystery, though, hope and faith allow one's continued attention to shadows, ghosts, shells of former selves, unrealizable realities. Thus,

It might be possible
 I keep on believing
 I keep on praying
 I keep on giving
 I keep on trying.

This short anonymous poem, taken from the May 1982 issue of the San Diego newsletter, expresses the urgent belief in the possible. What that is is not specified. No matter, for the poem is not about anything in particular; rather, it conveys faith, the mystery of belief.

Inscrutable faith is also part of portrayals of children's related disease experience. One child's poem, 'Just because...', written by Kathleen Siegle, explains love and devotion by, in effect, not explaining it — something which, prosaically, begs explanation. To an implicit question about her continued caring, she responds 'just because'. The poem tells of what all the disease's poetry informs us — that mind, self, and meaning are objects of experience which, in the final analysis, are faithful

preservations (Gubrium 1986b). Taken from the March 1985 issue of the Ann Arbor, Michigan newsletter, the poem reads:

One of my Grandmas
Gives me Hugs
And sends me cards in the mail
On my Birthday
And sometimes
'Just Because.'

One of my Grandmas
Can't remember
Who I am
Or what day it is ...
So I give her hugs
'Just Because.'

The structure of poetic documentation

A broad glance at the poems shows that their words reference the range of significant topics and concerns believed to constitute the disease experience. Yet messages are conveyed at two levels. On their surfaces — what their words reference directly — the poems tell us about concrete things and concerns known and conveyed by other means: the substantive matters, the information that words are expected to communicate. At the same time, *each* surface message is also about its depths, the unspeakable underpinnings of every expressible topic and concern of the disease. While a poem might be about the familiar topic of memories, as in 'Heart's memories', it is simultaneously about an aspect of memories that cannot be put into words: *heart's* memories. While a poem might reference the need to understand the patient's increasingly inscrutable conduct and speech, it also directs attention to the depths of understanding, toward the achievement of unspeakable insight into another.

As surface messages, the words of the poems are positive in that they are about the readily evident disease realities referenced. But as poetic messages the poems negate the realities referenced without restoring separate contents. The term 'negations' highlights this non-positive quality of each object of experience. Negations are not opposite substantive categories — not, say, hate in opposition to love, remembrance as opposed to forgetfulness, or feelings in contrast to thoughts. Rather, negations are empty categories reflective of incommunicable disease realities. Even the term 'feelings', while regularly used to denote a domain

of the incommensurable, refers both to denotable feelings — positive, communicable realities such as love and hate — and to their incommensurable depths, what plain words cannot convey about them. The surface and deep messages of the poems are intertwined. Words serve as markers for their own negations, just as negations — incommunicables — convey poetically what their plain words cannot: a synergy of paradox.

By means of poetic documentation, each substantive communication conveys the depth of its particular experience. For example, while a poem is ostensibly about the memory of a loved one, its poetic presentation and reception concerns what memory essentially is about, what the plain language of remembrances does not relate in its own right. As such, the poetic usage, say, of the word 'memory' is both a communicative device and a communication, meant to be both empty and full of evident meaning, used to stand for something which no word can represent, yet which every word positively communicates in its own way, simultaneously negative and positive signs of experience.

While those concerned for the welfare of the patient are reminded that dementia takes understanding, care, and commitment, they are also told that all of that is still not enough. While caregivers are repeatedly cautioned that they must care for themselves, too, they are also warned that there is more to self-concern than personal circumspection. Caring, it is said, goes beyond all the things we think and do, day in and day out, for the patient and for ourselves. Indeed, it is evident that if one had access to an inexhaustible fund of descriptions to represent what those 'beyonds' were, they still could not be put into words. They are, simply, among those things that no words can communicate, all the incomprehensible things that we try, but fail, to describe to ourselves and to each other — every word's negation; real but empty categories.

Some poems and usages are more suggestive than others in pointing to the need to penetrate the ineffable depths of concern, the belief that behind or beyond each consideration is a matter of the heart or soul. For example, a poem entitled 'The picture', reprinted in the Summer 1984 issue of the Kansas City newsletter, informs us that there is something more to the person than one can see or hear.

Look in my window
 Look close and deep
 Past the shroud that surrounds me
 Past the mask I keep.

Touch me with kindness
 With tenderness and love.

Watch through the window
My soul gently move.

If you could see past the picture I paint.
If you'd look for a moment past my restraint
You'd see in my window a person so real
One who still senses, and touches and feels.
Lost in a tragedy, now it appears
Life's treasured memories of years and years.

Look in my window through my eyes to my heart.
Give me last measure before we must part.

Look in my window
Look close and deep
Past the shroud that surrounds me
The vigil I keep.

Elizabeth J. Skow
Olathe Good Samaritan Center

Written by an institutionalized patient, the poet asks the reader to look past all categories of describables, past what she appears to be. While the poet puts the beyond in words — in terms of soul and heart — it is evident, too, that these are mere words for what they are meant to convey nonrepresentationally, something beyond windows, shrouds, and masks.

In a plea for something beyond understanding, another poem, reprinted in the May 1985 issue of the Duke ADRDA newsletter, distinguishes care accomplished from something more. The line-by-line distinctions are not as forcefully poetic as the overall message that each successive 'more' negatively impels us toward.

Do more than exist, live.
Do more than touch, feel.
Do more than look, observe.
Do more than read, absorb.
Do more than hear, listen.
Do more than listen, understand.

John H. Rhodoes
Courtesy ADRDA Orange County, CA

While the poem has a last line, its conclusion is not a definitive ending. Doing more than hearing is listening; doing more than listening is understanding. What, then, is doing more than understanding? We seem to run out of words to express that something else which plain words cannot communicate. Still, poetically, whatever that 'more' is, it is

nonetheless taken to be there. Its 'thereness' makes it sensible to communicate. Even though in a certain respect the poem could be read as a plea for greater and more genuine caring, it is also evident that the lack of an end-point in its thrust toward 'more' directs its reader without a positive guidepost. Every positive answer to each question of what 'more' is urges us, time and again, to still more. As such, the poem is as much a negation as it is a series of positive directives, poetically documenting the devoted depth of caregiving.

As the positive and negative levels of description reference two inextricable domains of experience, they have a common range of application. One domain is the range of all possible communicable matters — in this case, the sum and substance of disease matters, from its neuropathology to its nursing care. The negative domain contains the side of all aspects of the disease experience that cannot be put into words. The negative domain is at least as vast as the positive one, for each positive feature of the experience has its unknowable depths. There are certain areas of every aspect of the disease's neuropathology, it is said, that 'we'll just never know about'. In regard to devoted caregiving, it is frequently remarked that words cannot possibly tell what it takes to face the slow death of a once bright mind. As far as the patient is concerned, even though there may be a lack of cognitive ability, there are still messages of the heart, the meanings and intentions that lie behind the gestures and confused speech. In its potential application, poetic documentation discerns the inscrutable domain of all experience.

Conclusion

Thomas and Znaniecki (1918–1920) collected and used the written contents of the letters of Polish immigrants to reveal the personal side of social change — how the process of immigration translated into shifts in self-perception and altered interpersonal relations. The current international interest in life stories (Bertaux 1981) does much the same; through the analysis of the life stories of individuals who have experienced select or diverse historical events, the human side of history and social change is documented. Poetic documentation, in contrast, cannot be approached in this fashion. Authors' experiences are not straightforwardly written on the poems' surfaces. It is not so much the plain words — the simple content — of the poems that document the depths of disease experience as it is what the words do not convey, their negation. The method of poetic documentation suggests the need for a different approach to the personal documents. Poetic usage requires that one analyze not only content, but

also the way poems enter into the concrete experiences which they are about. Although Alzheimer's disease's folk poetry is written, its communicative organization cannot be separated from usage. In contrast to written testimony, folk poems do what they do because they are poetic in format and are presented as non-prosaic. By and large, the traditional approach to personal documents has ignored everyday usage.

Respondents' communicative methods tell us something about the completeness of social science methodology. As far as poetic messages are concerned, a resultant methodological complication is the distinction between the surface and incommunicable texts of a document. This is not merely analytically cautionary; those who use poetry to document their experience themselves tell us that the words are not as important as the message. Another methodological complication is how the surface and incommunicable references of folk poems document experience. It is evident that we must do something other than just read the poems to understand them as those concerned do. What is required is the observation of usage, of reading and reception. As such, the personal document is not necessarily just a vehicle for revealing conduct; it can be conduct in its own right. To borrow two terms from Barthes (1975), the texts of some personal documents are more 'writerly', less 'readerly', than personal documents traditionally have been taken to be, demanding more than content analysis.

This brings us to the conduct of documentation. Thomas and Znaniecki, and others who have used personal documents, work within a passive mode of interpretation (see Denzin 1984). For example, the letter or the diary is taken to be a written representation of what it purportedly references; contents more or less stand in one-to-one correspondence with experience, revealing it point by point. A notable exception here is the diary diary-interview method formulated by Zimmerman and Wieder (1977), where diarists are asked to expand upon and interpret in interviews what they had written earlier in diaries about their experiences. Together with poetic usage, this suggests that the term 'documentation' can have a more active meaning, where authors and audiences both enter into a documentation process.

Taking usage into account, any personal document can be seen as doing two forms of communicative activity. First, whether letter, diary, or poem, what is written — the substance of the text — documents what it is believed to be straightforwardly about. This is passive documentation, in that the document is approached for its surface message and properly left when that message is obtained. Of course, in a certain sense all passive documentation is active in that readers must cull messages from words — from beneath words' surfaces, as it were — which borders on the communicative synergy of substance and incommunicable.

Second, what it means to read can be more than a technical exercise correctly getting the message. Against the larger issue of the social organization of communication, it can mean that — with regard to different understandings of the relation of text, conduct, and understanding — the medium is concertedly part of the message (see McLuhan 1966, 1967). As such, active documentation takes both reading and usage into account. In this regard, documents are passive only insofar as our attitude toward them is such that we take them and not us to be the conveyers of their messages. Poetic documentation specifies active documentation suggesting that our working approach to messages be negative in that we are to pay less attention to what is plainly conveyed by words than to what they do not, yet admittedly do, manage to tell us.

As noted earlier, the disease's folk verse is rather crude and grossly sentimental. Love, devotion, heart, soul, spirit, and memories are prevalent terms and themes. But the sentimental language is not merely mushy. It cannot be judged simply for its poor expository quality in comparison with how 'good' writing might better convey the intended message. The folk poems do something with words other than exposition. For that purpose, the folk poems *are* good writing, perhaps the best writing; for usage turns us away from substance to the depths of the experience, references, and does so in fine form.

Some might conclude that what has been noted here about poetic usage and the structure of poetic documentation has been said many times over in literary studies. But the fact that something we might call 'poetic behavior' is discerned to have the same organization and purpose as poetic literature is significant. In view of folk usage, of which this is a case study, it would be a mistake to limit the poetic to what falls in the formal domain of poetry. Indeed, in their untutored way, folk poems and poetic instruction instruct us in the entire range of the poetic documentation of experience. As suggested at the beginning of the paper, a similarly narrow vision short-changes the methodological understanding of content analysis something which a serious consideration of documentation-in-use would serve to remedy.

References

- Barthes, Roland (1975). *S/Z*, trans. by Richard Miller. London: Cape.
- Behnke, John A., Finch, Caleb E., and Moment, Gairdner B. (1978). *The Biology of Aging*. New York: Plenum.
- Bertaux, Daniel (ed.) (1981). *Biography and Society*. Beverly Hills, CA: Sage.
- Denzin, Norman K. (1984). Reinterpreting the Polish peasant. In Florian Znaniecki & Z. Dulczewski (ed.), 61–73. Warsaw: Polish Scientific Publishing.

- Gubrium, Jaber F. (1986a). *Oldtimers and Alzheimer's: The Descriptive Organization of Senility*. Greenwich, CT: JAI Press.
- (1986b). The social preservation of mind: The Alzheimer's disease experience. *Symbolic Interaction* 9, 37–51.
- (1987). Structuring and destructuring the course of illness: The Alzheimer's disease experience. *Sociology of Health and Illness* 9, 1–24.
- Gubrium, Jaber F. and Lynott, Robert J. (1985). Alzheimer's disease as biographical work. In *Social Bonds in Later Life*, Warren A. Peterson and Jill Quadagno (eds.), 349–367. Beverly Hills, CA: Sage.
- Johnson, Horton A. (ed.) (1985). *Relations between Normal Aging and Disease*. New York: Raven.
- Katzman, Robert (ed.) (1983). *Banbury Report 15: Biological Aspects of Alzheimer's Disease*. Cold Spring Harbor, NY: Cold Spring Harbor Laboratory.
- Lacan, Jacques (1977). *The Four Fundamental Concepts of Psychoanalysis*. New York: Norton.
- McLuhan, Marshall (1964). *Understanding Media: The Extensions of Man*. New York: McGraw-Hill.
- (1967). *The Medium is the Message: An Inventory of Effects*. New York: Random House.
- Plummer, Ken (1983). *Documents of Life*. London: George Allen and Unwin.
- Tomlinson, B. E., Blessed, G., and Roth, M. (1968). Observations on the brains of non-demented old people. *Journal of the Neurological Sciences* 7, 331–356.
- (1970). Observations on the brains of demented old people. *Journal of the Neurological Sciences* 11, 205–242.
- U.S. Public Health Service (1984). *Progress Report on Alzheimer's Disease: Vol. II*. U.S. Dept. of Health and Human Services: NIH Publication No. 84-2500.
- Thomas, W. I. and Znaniecki, Florian (1918–1920). *The Polish Peasant in Europe and America*. New York: Dover.
- Zimmerman, Don H. and Wieder, D. Lawrence (1977). The diary diary-interview method. *Urban Life* 5, 479–497.

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