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Narratives of Elder Parental Death: A Structural and Cultural Analysis

This article reports on middle-aged daughters' perceptions of the experience of parental death. One hundred three married women, aged 40–62, were interviewed about six months after the deaths of their widowed elderly mothers using an in-depth qualitative interview format. As part of the interview, informants were asked to "tell the story of your mother's death," a question designed to elicit a subjectively based narrative account. Analysis of these narrative texts discovered a number of salient themes: the quality of medical care; the personality of the mother; issues of health decision making; the salience of the death scene; and mother-daughter closeness at death. Issues of family dynamics were quite important and permeated each description. In general, the narratives disclosed four aspects of the elder parental death experience: the enmeshment of medical care with the story of the death; the occurrence of pervasive ageism in accounts of the death; impossible dilemmas in terminal care of the aged; and the irreducibility of subjectivity in the daughter's biography of her mother. [death and dying, biomedicine and aging, intergenerational relations]

Death in American society is increasingly medicalized. The accounting, certification, and processing of death evolved as part of social scrutiny of the person and social control of the body in changing power circumstances (Turner 1985). The experience of death is thus decreasingly a community or a congregational event and instead the business of a diffusely defined family, a social network, or "the immediate family."

Death also increasingly concerns people who are of advanced age. Dramatic changes in the life expectancy engendered by changes in medical technology and public health practices have led to the "graying" of many societies, including the United States, to an increased concern with all aspects of aging, and to an unfortunate popular equation of advanced age with chronic illness (Sankar 1984). An important area of these changes has been in family structure and relationships.

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For example, the situations of adult family caregivers for impaired elders have received a great amount of scholarly attention (Abel 1987; Abel and Nelson 1990; Dalley 1988; Finch and Groves 1983).

One aspect of these changes has been largely overlooked however: the now-common experience of parental death and generational succession in the middle years of adult life. In America, most people are in midlife when their parents die. It has been estimated that about 5 percent of Americans have a parent die annually (Perlin and Lieberman 1979). In 1900, parental death was experienced by some 25 percent of all children by the age of 15; by 1976 that figure had dropped to 5 percent (Uhlenberg 1980). Winsborough (1980) estimated that in 1920 about 45 percent of women aged 50 had a living mother, while in 1970 this figure was nearly 75 percent. He also estimated that in 1976 some 86 percent of married couples in their early fifties had at least one living parent.

Similarly overlooked has been the death of elders. In part, the research described in this article was shaped by a lack of scholarly attention to the death of elders (Moss and Moss 1983–84). Culture structures the value of people who die—the value of their loss to society. In American folk theory, the most on-time and normative deaths—those of old people and of elderly parents—stir less reaction than do the deaths of spouses and siblings. And the deaths of children are considered the most unnatural and painful, the worst sort of death (Goodman et al. 1992; Klapper et al. 1994).

This article describes some results from an ethnographically based research project designed to shed light on how middle-aged daughters experience parental death. A sample of middle-aged women were asked to tell the stories of their elderly mothers' deaths. Analysis of these narrative texts discovered a number of salient themes: the medicalization of the death; the quality of medical care; the personality of the mother; issues of health decision making; the salience of the death scene; and mother-daughter closeness at death. In general, we found that the narratives disclosed four aspects of the elder parental death experience: the enmeshment of medical care with the story of the death; the occurrence of pervasive ageism in accounts of the death; dilemmas in terminal care of the aged; and the irreducibility of subjectivity in the daughter's biography of her mother.

Methods

The data reported here were gathered in a research project entitled "The Middle-Aged Child's Experience of Parental Death." The goal of this research was to understand how a sample of married women ($n = 103$), aged 40–62, reacted to and interpreted the recent deaths of their elderly widowed mothers. The women were interviewed initially between three and six months after the mother's death and then, when possible, a year after the first interview. Informants were recruited in Philadelphia and the five surrounding counties by newspaper ads (53%), from local health, welfare, and hospice agencies (12%), from former research registries (11%), by personal contacts of respondents or study staff (10%), by references from clergy (8%), and from other sources (6%). All informants were married. They averaged 2.5 living children, and the average household size for each was 2.8 persons. The respondents were predominantly European-American, were 52 years old on average, and were largely middle class economically. All but one were high

school graduates, and 42 percent had completed four years of college. Sixty-three percent of the daughters worked outside their homes. The average age of their mothers at death was 81.

The interviews followed an open-ended, ethnographically based conversational style increasingly used in anthropological gerontological research (Fry and Keith 1986; Reinharz and Rowles 1988). They were tape recorded and transcribed.

In this article we analyze one small part of the overall interview, but one that elicited, in an unstructured way, some of the most detailed and telling responses. Immediately after the initial brief collection of background demographic information, we asked respondents the following question: "Can you tell me the story of your mother's death? What happened? How did she die?" In the sequence of questions following this one, we asked the informant to describe what the last few months of the mother's life had been like as well as the informant's initial reaction to the death. In addition to background demographics and the story of the maternal death and informant's reaction to it discussed here, subsequent items covered the quality and nature of the personal relationship to the deceased parent; the effects of caregiving or nursing home residence on the relationship; relations with other family members; changes in self and personal identity with the death; changes in sibling relations (if any); and, finally, the personal meaning of the death. These responses are not treated here.

The placement and nature of the question in the overall interview procedure served several purposes. Occurring immediately after the collection of somewhat bland background materials, the question served as a grounding in the overall topic of the interviews. Further, it permitted the informant a large degree of control in constructing a narrative account of the events surrounding the parental death.

Informants had many options in their narrative task. For example, the story could have been told as an extension of the mother's whole or prior life or as a story specifically of accomplishment, transcendence, triumph, or generativity. Indeed, the demand characteristics of the overall interview stressed that our research group, as interviewers, were interested in personal meaning (whatever that might be to each informant) and the daughter's interpretation of both the mother's life and her own, rather than in the specific medical details of the death.

In essence, we asked for a narrative account—the story—of the parental death. Story telling or narration is one of the most significant human activities. The act of "somebody telling about something to someone else" (Smith 1980) serves many social and cultural purposes but may be viewed primarily as a way of relating individual experience to larger explanatory or sociocultural contexts (Brody 1987). Thus stories represent an important mode by which people organize, display, and work through experiences. Gee notes, "Probably the primary way human beings make sense of their experience is by casting it in narrative form" (1985:11). Cohler calls personal narratives "the most internally consistent interpretation of the presently understood past, experienced present, and anticipated future" (1982:207). Bruner (1986) has identified "the narrative mode" as one of two human ways of knowing. Narration often involves two relational aspects: first, the narrator organizes experience both for another and for herself at the same time; second, the narrator involves others as active listeners. In our study, responses to the request to "tell the story of your mother's death" ranged from short accounts in chronologi-

cal sequence to lengthier, multidimensional and emotional explications (some up to 15 single-spaced pages of transcribed text).

Informants were divided into four categories: women whose mothers had spent at least six terminal months in a nursing home ($n = 27$); women who lived out of town (at least two hours by car) from their mothers ($n = 28$); women who spent substantial time in the last six months involved in "heavy," complex, and often exhausting personal caregiving for their mother ($n = 19$); and women who engaged in light or no caregiving, including those informants whose mothers died rather suddenly ($n = 29$). This interview design was employed so that we could assess some issues in the fields of death and dying, gerontology, and caregiving that are beyond the scope of this article.

Interestingly, we found that although there were clear plot differences (for example, sudden death versus lengthy terminal illnesses), and some structural differences (reported below), there was no correlation between these categories and the general themes we describe here. Indeed, our group assignment criteria (nursing home, heavy caregiving) were used variously and disparately by individual narrators.

The Narratives

Typically, most narratives were a complex interweaving of symptom description, events of the illness, episodes of interaction with the medical establishment, an evolving process of awareness of the terminal decline, ongoing family dynamics of conflict and amity, awareness of the mother as a living person, and health care decision making for which the daughter and others were frequently unprepared and overwhelmed. As discussed below, some featured a medical preamble that described the onset of decline.

Structurally, there were some narrative differences among the four categories of women. Accounts were shortest for the "light" and noncaregiving daughters, and these often lacked lengthy medical preambles because the terminal period for the elderly mother was often brief. Accounts by the other informant groups were lengthier; those by "heavy" caregivers were the lengthiest and the most emotionally detailed.

In general, informants used a "line of decline" approach charting key medical events and acute crises as though they were graphed points of declivity. They thus merged two cultural constructions: illness as a representation or metaphor of decline was merged with chronological aging as a representation of bodily decline. The larger question of the cultural conflation of aging with illness through the metaphor of decline is an important issue that cannot be fully discussed here. Nevertheless, as with much belief concerning old age, there is ample evidence in these narratives for it.

What is perhaps most remarkable about these narratives is the extent to which they implicate medical practice as part of the story of the death, indeed as *the* story of the death. We also found in the narratives considerable evidence for ageism in medical practice as described by the daughters. In some cases the ageist treatment of an elderly parent by a physician was clear and overt. Some daughters described physicians and others as telling them nothing could be done for a parent *because*

she was old. Other examples were more covert and involved, for example, apparent lack of effort or care (because the person was old, or for some other reason).

Another significant concern of these narratives is the fundamental, insoluble dilemma of medical care and of death and dying in later life. For example, should an 86-year-old person be the object of major surgery that may be painful, uncomfortable, life threatening, and may add no quality time to living? Not all the narratives discussed such issues, but they constitute an important subtext throughout, especially for informants whose mothers were in a long-term or chronic care context with acute episodes. Such questions have been discussed in detail in the large bodies of literature on aging, advance directives, and medical ethics, but there are of course few clear guidelines for all situations. Essentially, such questions can assume that, because of their advanced age and nearness to death, older people are a different, lesser kind of person than "normal" people. In this line of thought, the elderly are people about whom such questions must be asked because they lack much remaining life and, possibly, because of a pervasive feeling that their life is less valuable than those with more time before them. Implicit in many narratives is the question of the worth of life at the end of life and the painful negotiation of physical suffering versus survival.

A final concern is with the unmediated polarities of, on the one hand, life history, biography, or the person's interpretation of her own subjectivity (Good 1990; Kaufman 1986) and, on the other hand, the "external" realm of biomedicine. To the extent that effective biomedicine and health care require integration with patient worlds of meaning, these narratives illustrate that the alienation of both mother and daughter is enhanced because of the ways in which medical practice may at times be seen by them as impersonal, irrational, and incomprehensible. There are moments in these tales when components of medical practice appear to informants poorly integrated, unclear, and unstable: personnel and settings seem to come and go and situations are described negatively as changing rapidly. Interestingly, for many informants, facticity—the social construction of facts—concerning the mother's diagnosis is only partially facilitated or legitimated by physicians and others in authority. There is a concurrent process by which the narrator-daughter herself identifies, over time, the "true nature" of the mother's medical state of being. And, in extreme cases, the daughter is challenged to see the mother's "true personality" through change.

It is important to remember that these narratives do not, strictly speaking, illuminate the subjectivity of the infirm mother. Rather, these are the daughters' interpretations of their mothers' subjectivities. Indeed, because of cognitive impairments of many mothers, many daughters were truly interpreters of what they felt to be their mothers' moods, ideas, desires, and intentions. These daughters, through their narratives, engage in a process of co-biography (Geertz 1983; Luborsky 1987). Many daughters were responsible for caring for and expressing the compromised selves of their impaired mothers. However, they also looked for evidence of their mothers' continued selfhood, despite reduced circumstances of self. These accounts are in part biographies of the mother, but they are also statements of selfhood by the daughter because they are accounts of materials that have been internalized and matter greatly in the personal meaning system of the daughter.

These concerns will be apparent in the case materials we present below. Analyzed specifically for content, most of the narratives were concerned in general with one plot and five thematic areas, as follows. First, many of the narratives featured a medical preamble that not only set the stage for the story of the death but also clearly signaled the medicalized content of the death. Second, almost all narratives took stock, in some way, of the quality and experience of medical care. All accounts involved deaths in the often disorganized context of the standard health care system. Third, many of the descriptions were concerned with the personality and temperament of the mother, how the mother did or did not manage with the course of the terminal illness. Fourth, many accounts voiced struggles or concerns with medical or ethical decision making, and the lack of clarity in this regard. Finally, many of the narratives, though not all, made some accounting of the "death scene" or the very last moments of the mother's life. This theme was often concerned with the possibility of closeness with the mother at death.

Themes in the Narratives

The Medical Preamble

Many of the narratives began with a long "medical preamble" that reviewed the health status and history of the mother and followed with a description of a recent period of heightened awareness of the possibility of death. For example, consider the beginning of the account by Mrs. Silva, aged 56, whose mother died in a nursing home at 82:

Well, she was, she died quietly. But I would say that she had a terrible, terrible last year. She had had a stroke and just before Thanksgiving of '88, and it was, she had brain damage, and was rendered speechless and could not speak. And she, I was just home with her. And so, she lived, that was, as an almost vegetable, [for] a year. So she had a horrible last year. And I could never figure out how much she knew or didn't know. It was very hard because sometimes she could squeeze your hand and make me feel she knew who I was.

This account describes the bare bones features of a terrible terminal year. The account begins chronologically, but attempts at a logical ordering are immediately overwhelmed with statements that communicate the general experiential sense of the period ("it was a terrible year") and the account is punctuated by description of deeply felt episodes of personal dilemma ("she could squeeze your hand and make me feel she knew who I was").

A more orderly medical preamble is given by Mrs. Brown, aged 48, whose mother, aged 84, died in a nursing home of heart disease:

I knew that, the last few weeks before she died, that she wasn't as robust as she had been, and actually her health had not been as good the last year prior to that because she had gone into congestive heart failure in the summer of '88. And I was out visiting my sister at that time, when the doctor called us home. But she pulled through and went back to a fairly normal schedule. She joined us all for Christmas in Washington, D.C., but then during the summer of '89, she was more tired and stayed in her room more. She was even having meals in her room. . . . And then, the day she died. . . .

At this point Mrs. Brown provided a detailed (several pages of text) description of the events of the last day.

Most informants used a narrative of decline element. The narrative stage was set as the transition from normalcy to terminal decline began. In all such cases the story of the death was medicalized.

The Nature and Quality of Medical Care

The vast majority of the respondents chose to medicalize the story of their mothers' deaths. They surrounded the story of the life or the mother's subjectivity with episodes of medical decline and the moral dilemmas of care and treatment.

For example, the account of Mrs. Grant, a 49-year-old "heavy" caregiver whose mother died from complications of diabetes at 77, summarized her mother's medical history. This account is typical of a chronological style of narration that often interdigitated with a more subjectively oriented account of the mother's life:

I noticed two years ago that there was, that she was having physical problems during—I wouldn't say minor ones—she started with diabetes, which was controlled by full medication, and then she had to have insulin which she administered by herself, which I find remarkable, at her age. She was 75 then and twice a day she injected herself. I noticed that her memory was beginning to fail her. . . . I noticed she was having problems occasionally with her walking. . . . She could catch herself but, you know, at that time I didn't realize that she had had one or two falls that didn't resolve in any kind of injury that I had seen. In September of '88, she had a fall, a pretty good one. She called me and she said, you know . . . she had to tell me she fell because I would be picking her up in a day or so and would see this pretty unusual sight. . . . Well, I went to pick her up on a Wednesday and one side of her face was all bruised, big gash. You know, she should have been taken to the hospital and checked.

The account details a series of more frequent and serious falls, and then:

And even she began to notice, you know, something wasn't quite right. All the testing they had done, they said, you know, her mental ability isn't that impaired. And I kinda laughed because in January they had said that she was kinda, like, not too bad for a woman who had seen multiple decline in systems. And I kinda laughed because I wanted to come [back for testing] this year. And they said, "Well, bring her back next year and we'll, you know, assess her. This will be a relative point from which we can determine how gradual her decline is becoming." [So] I call them a year later to say she's dead.

She really started to fail in January. . . . I brought her down to my brother's house for Christmas Eve . . . and when I went down there, my sister-in-law was very disturbed and she said, "I gotta talk to you." She says, "Mom is pissing herself." I said, "What?!" I said, "What do you mean?" She said, "No, I'm serious." She said, "All over the couch." She said, "Something's funny with her." I said, "Why didn't you let me know? . . . Why did you wait 'til ten o'clock at night? We're supposed to be going to [Christmas Eve] Mass." And I was angry at my sister-in-law for not calling, but then I realized that she had not seen her like this, you know, and so she wasn't prepared.

The narrative presents an extended story of medical history and decline, the occurrence of multiple symptoms, interactions with doctors and family members,

and her mother's desire to be at home, not in a hospital, until her death some months later.

Besides its function as a chronological account of physical and mental decline, this text illustrates another important component of awareness communicated in many of the daughters' narratives, the story of how all involved learned about what was going on, the uneven distribution of knowledge and responsibility, and, by default, the identification of relatively high degree of burden and moral responsibility for the narrating daughter. She knew more and therefore had to do more for her mother.

The narration of the illness experience by daughters also serves to illustrate the process of how erratic and unfortunate medical symptoms are socially factualized through the management and use of their knowledge and potential meaning. In many narratives the facticity of the illness is established with reference to the daughter's experience of the mother's symptoms and the familial discovery and legitimation of the knowledge of the symptoms. This is in contrast to those elements of the story of the death that are portrayed as the physician's to legitimate, for example, confirming diagnosis or listing alternative possibilities. The daughters expected the physicians to do a good job, to be technically knowledgeable, to act with concern and care, to take the necessary time, and to be polite. There is, however, no underlying belief in the omnipotence of doctors in these narratives, in part because so little possibility of cure seems to be offered by the doctors or expected by the daughters, because the patients are "old." Thus, while the symptoms and conditions exist within the body of each mother, they fall within the realm of the daughter's co-biographical work. Knowledge of these symptoms is also a socially shared burden within the family that requires shared awareness among those concerned.

The issue of medical and moral dilemmas was an actual part or a fear in many of the accounts. Consider the narrative of Mrs. Henry, a 53-year-old "light" caregiving daughter, whose mother died of cancer and stroke at age 86:

We took her to the doctor and he examined her and we waited outside. And then he called us in the room and we didn't want Mom to know she had cancer. For some reason, we were afraid to tell her that. Because we thought it would make her disposition or her whole self just worse. And she was trying to fight, to get [well], to stay well, you know. She did take care of herself and had been trying to stay well. And you could see her failing. You knew she was failing. And he called us in the room . . . and he told us definitely there was a problem, and the way they worded it, she kind of knew it was cancer, because they said it would travel through her whole system. And she would need surgery. And he was trying to tell us, like, in the surgery, what they would do. But it was all just, like, you couldn't absorb it, you couldn't really understand what they were trying to say. I said, "Mom's 86 years old." I said, "You know, can she go through this type of surgery?" And before that we had taken her to another type of doctor, too, for . . . a physical. And we took her to about three doctors before we made the final decision. And they said, "Yes," that is, if she didn't get it [have surgery] the cancer cells would go all through her body. And it wouldn't be a very pleasant death for her. So, when they tell you that. . . . But then . . . I think, "Look how she died anyway." So was it worth it? [She eventually had a stroke and died from that.]

And then I said to Bill [her husband], "What should I do?" He said, "If what they tell you is going to happen, she'll bleed to death." God only knows what kind

of pain she could have. It was like, we were like, it was like a nightmare. And then we were [back] in the doctor's office. I said to her [the mother], "Mom, it's major surgery. You're going to have major surgery." And she says, "The doctor thinks I can get through it. I'll be all right." And it's like, I don't think Mom really understood how bad it really was. Because we made the final decision, and we took her to the hospital, and the operation seemed like it was so long before the doctor came up and finally spoke to us. And he said, "We got all the cancer." But when they washed her stomach and had to clean her off for the operation, to prepare her for the operation . . . he said that the skin was so thin on her side, that there was an incision there. She had had this hernia that laid over here and kind of rubbed in her. Mom was heavy across the stomach and the skin just rubbed. It had broken open there. Then he said something about lymph nodes in the side too. And that incision never healed and had to be drained and cleaned. And then when she came back from surgery, I can still see her face! And she looked up at me and she was all . . . oh, my sister and I both cried. She had blood on her mouth and some coming out of her nose. And she said to me, "Annie, I didn't know it would be this bad." She looked up at me and I just kind of looked at her. I didn't know what to say to her. And I said, "You'll be okay, Mom."

The decision for surgery, before the death, did not thus appear to be based on any "true" knowledge of the mother's condition, but rather on fear of the worst aspects of the cancer and advice from several medical experts.

Such dilemmas were part of decisions these daughters made in concert with their mothers and siblings when possible, but many medical dilemmas are clearly compromised by ageism. For example, Mrs. Kooper's mother, aged 80, died from a massive infection after surgery. Mrs. Kooper noted:

Every three months she would go for a routine visit. She'd tell the doctor, "I have pains in my stomach. Everything hurts me. I have no appetite." And the doctor would more or less say, "Well, you know, Hilda, you're 79, and you don't have much activity. It's gas." And my mother, being of the old school, did not question [physicians]. Even if I questioned, it was always, "Well, you know, your mother is old." . . . You're taught to believe doctors, and you hope that they're right. But they're not always.

Another way of reframing the dilemma is in the context of the conflict between personal, biographical, or subjective experience, and chronological or biomedical time. Mrs. Glass, a distantly residing daughter, aged 59, told the story of how her mother, aged 86, was admitted to the hospital for her terminal illness. The doctor suggested her mother be admitted through the emergency room, rather than as a "normal" patient:

We get mother into the emergency room. . . . That's just a matter of waiting and waiting and waiting. . . . The red tape at that emergency room really was debilitating and very, very upsetting to both my mother and me. It was one precious golden day that did not have to be lost in her life. She didn't need that. I counted. The minutes were important. The days were important.

All in all, a substantial number of the informants described some aspect of their mother's care negatively. Certainly, some of these incidents are quite minor, but it is important to note that they have become a part of the overall death story, as illustrated below. Very few physicians or other medical personal described in the stories appear to be specialists in geriatric medicine, but rather in general

medicine or other clinical specialties. Further, many difficulties in medical care appear to rise from chronic miscommunication among institutional sectors and personnel in medical care and a philosophy of patient care that is not patient oriented.

In some accounts, miscommunication between doctors and patients and their families is incorporated as significant material in "the story of the death." That such miscommunications are described in the narration is an interesting and significant fact; many daughters insisted on describing these events as disturbing and upsetting and as integral to the story of the death. Consider these circumstances described by Mrs. May, a 42-year-old "light" caregiver of her mother, aged 67:

My mother had broken her hip. She had fallen down the steps and couldn't get, couldn't call out for help or anything [because] there is no one there. She pulled herself, somehow—she was losing consciousness, going in and out—into the kitchen. She tried to get help, but she couldn't get the telephone down. Only because one of her friends called her everyday at 9:30 and couldn't reach her and knew that the answering machine wasn't on, knew that my mother was not scheduled to go anywhere, and then called me and we found my mother. . . . Because she had been laying on the floor for 14 hours, they didn't operate right away. She developed a fever. And because of her other illnesses . . . they could not operate right away. They had to stabilize her. She was operated on, finally, on Wednesday. The surgery went well. She was up, she was walking, she was standing, sitting in a chair, standing up. . . . The following morning when I got to work, I called her as usual. There was no answer. I figured, "Well, the doctor was in the room." I called again. There wasn't any answer, so I called the nurses' station. They said, "Oh, didn't we, didn't somebody get in touch with you? Your mother's in intensive care." I found out later that there was a message on the answering machine, our answering machine, that the doctor has just missed me going between places, from home to my office, that my mother had vomited blood, went into a coma, uh, and she died that afternoon. We watched her die.

Changes in the care environment that should be relatively minor also can have a major impact on the story of the death. Such are reflected in the story of a floor change told by Mrs. Garnett, aged 46, whose mother died at 78:

My mother was in a nursing home and she was on a feeding tube and she was unable to, she didn't speak and she didn't particularly know anybody. She knew I was there, kind of, sometimes, not a lot. And I could feed her. . . . I didn't particularly want to prolong my mother's life. Except that she had free will. And, see, I'm a firm believer that God gave my mother free will just like me. . . . She was on a floor at the convalescent home that was very caring. And they used to talk to her when they changed her. And, she went up on a floor that just, they just treated her like a stick. . . . And, you know, they just treated her like, all right, she didn't respond to a lot, but they didn't talk to her when they did anything to her and their care was lacking in comparison where she was. . . . I just knew in my heart they were going to kill her.

These narratives highlight the relationship of the experience of death with the events and practices of medical care. Components include the nature of diagnosis and prognosis; medical history and final decline; the facticity and authority of medical knowledge and its interpretation in caring families; communication within families and between medical personnel and the family; medical decision making

and moral dilemmas among the old, especially the very old and infirm; medical ageism; and the conflict between biomedicine and elder and daughter subjectivities.

The Personality and Temperament of the Mother

As part of the co-experience of the mother's biography and life, daughters were quite often keen to describe the mother's personality and what they could see of the role of her personal characteristics in her death. This was done in several ways.

Many narratives were concerned with the temperament of the mother and how this was transformed or maintained with terminal decline. By and large, how the mother's temperament was altered or how she resisted alteration was seen as an important part of the story of the death. Changes in personality were most often seen as indicators of decline. Mrs. Henry, aged 53, noted:

And we called 911 and we got her to the hospital. She sounded all right. She wasn't completely okay, because, from the . . . when the ambulance guys came, they said, "Fran, how old are you?" They asked her name and she knew it, and then they said, "How old are you?" And she said 38, and I thought, "Oh, here is this nifty, great, alert, capable, independent lady." It was awful.

Mrs. Marks, aged 44, described her mother's situation this way:

She looked fine. I mean other than the fact that she moved more slowly. But you had to understand. My mother, only up until like a couple months before she passed away, her, most people's run was her walk. Okay? She didn't know how to walk. She ran.

Dying at home was discussed frequently as a manifestation of the elder's personality and desires that could be fulfilled by the daughter. Dying at home was often viewed as an act that both resisted and recognized the disease process because it highlighted the mother's uniqueness while giving into the inevitability of death. Mrs. Grant, aged 40, noted:

And I said, "What's the matter?" And she said, "I can't get up." I said, "Oh, come on, Mom. You can get up." And she said, "No, I can't." And she really began to cry. And she wasn't that kind of a woman. She rarely complained of pain and would not get that emotional. Something was very wrong. . . . I realized at that point in July that, uh, the end was coming. You know, this woman was not going to recover, and she wanted, she did not want to die in a nursing home. She wanted to die at home. And I said, "Okay. I can deal with that."

Mrs. Green, aged 57, said:

I have been doing a lot of introspection, you know, about a lot of things. About, well . . . did I do the right thing? Cause I know, she had told me many, many times that she never wanted to go to a nursing home. And that I really had guilt feelings about [that]. But there was no way I could deal with her at home in the condition she was in. Of course, it was only two days that she was there [before she died]. If I would have known that, I would have taken off from work and, you know [cared for her], but I didn't.

Mrs. Candor, aged 62, described her mother's end this way:

That was when she stopped reading and stopped watching TV that we realized that it was [bad]. And mother always was an avid reader, so that was a bad sign. TV, eventually she lost interest in it. Couldn't concentrate, and her mind began to, you don't use it, it goes, and it was just a question of waiting 'til her body said, "I'm not [able]; that's it." And she decided, she really decided that it was time to go. She said, "I don't want to, anymore. I don't want any food. Just let me go to bed and sleep." And we did, and we were lucky enough to have a nurse who understood. And we could only do that at home.

Some mothers were described as facing the specter of illness with resolve, not giving into it. For example, Mrs. Grant noted:

So, we didn't push her to move in [with me]. You know, we let her make the decision. And then in May she, uh, we closed up her apartment. She never actually went back and she liked it that way. Yeah, she liked leaving there when she was able to walk [out]. [There's some people for whom] its almost an insult to their dignity and their independence to be seen that way [starting to physically slide downhill], you know to end up being carted out in a wheel chair. You know, people were noticing that she [mother] wasn't herself, and she was a pretty forceful individual, very dominant, very independent, very outspoken, and her mental abilities had begun to slip a little, but her physical [decline] was becoming more noticeable.

Finally, some daughters' narratives highlighted the strong imprint of the mother's personality on the manner of her death. Mrs. Stroehl, among several, attempted to attribute intentionality to the control of death, but was unsure if it really happened. She said, "I don't know why mother lingered on the way she did. You know, I wonder that, if she was afraid to die, or, you know, maybe it had nothing to do with it at all."

Some daughters were unsure what their mothers' subjectivities were. Mrs. Silva noted, "I have a feeling, yes, that there was a quiet look of desperation in her eyes. But I don't know whether that was wanting to get out of her body to give it up, or what it was."

Some believed their mothers controlled the process of dying until the very end. Consider the words of Mrs. Fair: "But for my mother, it [living with an oxygen tank] would have been dreadful. You know, she just couldn't have tolerated that. So, I think she just gave up."

Mrs. Cresson, aged 58, described the death of her mother, aged 87:

As a result, two days before she passed away, the doctor asked me whether I would like to sign the No Extraordinary Measures. And I decided I would, because I could not bear to see my mother suffer the way she was suffering, knowing full well that my mother might recover and be a vegetable. That would not have been my mother's chosen style. So I signed it on a Saturday and my mother got progressively worse within the next two days.

Mrs. D'Amico, aged 58, whose mother died at 78, stated:

I told her that . . . we were going to bring her home. She held my hand for about an hour, and she said, "I like that idea, I like that idea." You know. She was just so happy to come home . . . with the family, you know, it worked out really good, and I would do it over again.

While such issues can be phrased as topics relating to the mother's personality and its potential changes, in fact, and especially in cases of dementia, there was a more basic question of who the mother was as a person, a self, and what remained of her. Symptoms of this illness can include behavioral disturbances, acting out through hostile behaviors, and verbal aggressiveness. Finding the mother-who-was was often very difficult for daughters whose mothers were demented.

Issues of Health Care Decision Making

Many narratives involved presentations of similar moral dilemmas because the death of the elderly mother precipitated decision making about appropriate and desired health care. Issues were often morally unsolvable and the "objective medical facts" hard to interpret and understand. What is striking in these narratives is the suddenness, as well as the subtle nature, of such decisions. Most daughters felt unprepared in this regard. Most mothers lacked living wills and other directives, and many of the decisions they were called to make had little to do with the subject matter of such directives. Mrs. Berne, aged 51, described her situation this way:

They wanted to remove her lung; she already had angina. . . . And my mother was hysterical. She said, "No." And we said to her, after we had a sibling meeting. We had agreed at this meeting [to] whatever mother decided. If she wanted no operation we would support her; if she wanted the operation, we would support her. It was her life and we felt she had a choice. We didn't want to take this [from her]. She had always been independent, so we didn't want to come in and take over. Well, my mother made a choice by not making a choice, not verbalizing. She just wanted to come home. So, that's when I said to her, "Well, then, you're coming home. That's it."

Well, when [my sister] called the doctor, and he said, "I'm telling you right now, you take her home, she'll be dead in two weeks. And . . . I'm not going to be held responsible."

The day I went to pick up my mother from the hospital . . . I even brought a wheel chair, in case they [the hospital] wouldn't give us a wheel chair to take her out. He [the doctor] came in and said, "You know, Esther, I'm not responsible for this." So, we brought her home to Sylvia's house.

Mrs. Arnold, aged 45, a "heavy" caregiver, whose mother died at 79 of cancer:

And she never left [my home] after Thanksgiving. She stayed here for the rest of the time, except the last three weeks. While she was here, she got progressively, you know, weaker and weaker. We put a bed in the living room, and we had the hospice program come in and help us out and give us some support and stuff like that. . . . [This last phase] lasted three weeks. She was incapable of doing anything. . . . Prior to that she was coming to the dinner table, and we were going out, and we were doing things. But, you know, things got worse: I was feeding her, I was up all night, I didn't handle it well. We started getting in [home] care, 24 hours a day. Well, that turned out to be very expensive, so the suggestion was made and she was out in a nursing home. . . .

And she lasted only three weeks. So, I don't know. If I had known it would be only three weeks, would I have kept her here? I don't know. . . . [The decision to place her] was torture. I spent almost as much time at the nursing home when she was there, as when she was here. I went there, I was there for every meal. I fed her every meal.

Mrs. Hilton, aged 45:

We found out, I guess, the end of November, that she had cancer. And so, it was just a month 'til she died. Which in a way is fortunate, because she didn't have to suffer, and we didn't have to make any decisions about life support systems. So, I felt like, my prayers for the whole thing were answered.

Few accounts had the simplicity of Mrs. Jonas's:

She made her own decision that she didn't want that [surgery and possibly a respirator]. She said, "Just make me comfortable." She said, "You're not going to build up this old body. Just make me comfortable." So my sister and I honored her wishes.

All such decisions led to the moment of death. Of particular interest in these descriptions of health care decision making was the uncertainty involved in knowing what to do and the lack of a clear guiding voice from parent, family, or health professionals. In some cases the mother, through prior discussion or advanced direction, had left a fairly clear indication as to the limits and form of treatment. But in many cases such parental guidance did not exist, and all the choices presented to the daughters were seen by them as lacking or inimical. The medical care system too, because it was fragmented, did not provide consistent modeling or guidelines for full evaluation of health care decisions. In this environment the suddenness with which some decisions had to be made combined negatively with the range of uncertainties.

The Death Scene

Many daughters described the death scene as part of the overall narrative account. Not all daughters were, of course, present at the exact moment of death, but many were. In the most affecting narratives, the death scene could serve as an effective moment of closure, a key moment of family life, and a moment for transcendence of loss. In other instances the death scene was profoundly disturbing.

Mrs. Isaacs, aged 59, whose mother died at 90 of numerous ailments, noted:

The next day . . . she started to bloat. 'Cause I said to the nurses, "What's this? God, she looks like she's pregnant." All on one side and it was hard. And I said to my mother, "Does it hurt?" And I pushed. She said, "No." The next day . . . they called me: "Could you come over earlier 'cause it seems like we can't get through to your mother." . . . I went over there and tried talking to her, and she was, she was just, just talking away and nothing really made sense. And it wound up where she just talked and talked and talked and I tried calling her, 'cause they said, "Keep talking to her, she may recognize your voice, or she may recognize something you say." . . . But, uh, her eyes were open and looking, but it just seemed like she didn't see anything. . . . And she kept on talking. And a lot of it was about things from the past. But whatever it was, even when my brother and sister got there, we couldn't, umm, none of us got through to her. It just seemed like she couldn't hear us. Her eyes were just moving around . . . and she even suffered to the very end, I mean, in her own way. It wasn't a peaceful death, really.

Mrs. Cresson:

Most of the family was there, and my mother was having more difficulty breathing and I had her in my arms trying to talk to her, reassuring her that I loved her and one thing and another. And she died. . . . Yes, right in my arms, which was a beautiful way to die. It was like my mother's gift of peace to me, knowing that I could not have been any closer. She was just a beautiful person. But all through her last week, she kept saying, "God, God, why are you doing this to me? What have I done to deserve this?" And she kept calling for her mother and that really got to me 'cause her mother has been dead for forty years.

Mrs. White, aged 53:

She was still holding on. But of course, her body turned brown, her eyes were orange. It was a nightmare. . . . And so eventually, she suffered; the last day and a half it was a coma. How she was breathing, how she lived a day and a half, I don't know. Finally, I talked to her [in the coma], I said, "Mom, please let go. I know you can hear me." I said, "Daddy's there, eventually I'll be there. No one should live like this. You don't deserve to live like this."

Mrs. Martin, aged 53:

I know that when my Dad died, he was in a coma for 16 days. . . . And I learned then that they can hear you in a coma. So, then, I knew then in the hospital with my Dad to talk to him constantly and tell him don't worry about mother. So, when my Mom was in a coma, I, you know, kept talking to her and saying things like, "I bet you're surprised I'm here." And, "I'm going to brush your hair right now." And, I was brushing her hair and, just like that, she took a last gasp. And, I thought, you know, not being around patients that much, I thought she was coming out of the coma. So, I got really excited because she [breathed] like that. . . . And that was it. She took this breath and I'm brushing her hair and her head went down and that was it.

[We] immediately called the doctor. . . . The doctor came down and examined her and just said very quietly that your Mom has passed away and I'm very sorry. And he said, "What a beautiful way to go: surrounded by her family in her own home. Never having to go into a nursing home. Never being hooked up onto tubes." He said, "You are so blessed."

Mrs. Byron, aged 41:

My mother and I were never close. We had a very strange relationship. . . . But anyway, I was there to see her one day and she asked me to turn her on her side, and it would have been her side where her, she'd be lying on her hearing aid, so she wouldn't be able to hear me. And I went over and I said to her, "Is that OK?" And she looked at me and she had this, she had such anger in her eyes and she said, "Edna, I hate you." And she closed her eyes and she would not respond to me. And I waited for two hours; I sat in the room and waited for her, maybe, to want to be moved and so we could talk about it [what she had said]. And that didn't happen. And the very next morning I got a phone call that she was dead. So, so the very last thing she told me was that she hated me. I'm in therapy for it right now, you know.

This disturbing account suggests that one important goal outlined in these narratives is the negotiation of mother-daughter closeness and the transcendence of the loss. As noted, the process of realization of the terminal illness and the impending

death places the narrator-daughter in the role of a moral burden-bearer in relation to other social actors in the events surrounding the death. The final portions of the relationship also form the subject matter of these narratives, between descriptions of medical episodes and crises.

In many cases daughters were completely at the beck and call of their infirm mothers; in other cases their care consisted of frequent trips to visit the mother, phone calls, arranging for care, and management of the mother's well-being and quality of life, often from a distance. Daughters worked as best they could to fulfill their own expectations for filial devotion and desire for closeness and to overcome sometimes difficult relationships with their mothers.

Mrs. Caron, aged 52, whose mother died at 91:

I made the decision at that point, even though I said before that I didn't want to take care of her anymore. Her negativity just got on my last nerve. When she was sick, I just said, "Mom, I'm not gonna send you to a nursing home." I've been working for an agency for the last two years, and I did a lot of nursing home work, and I just think its a terrible way to die.

Mrs. Morgan:

I still insisted on her getting up and in a wheelchair. I propped her legs up. When she had to have a bowel movement, I insisted on putting her on the toilet or the commode. I tried to have this woman have a social and as normal a life as she would want. I always did her hair every week. She bathed in the tub twice a week. . . . I called the doctor and when my mother started coughing, bubbles were coming out of her mouth, and I knew there was something wrong, and the doctor said that she was going to order morphine . . . that she would be very peaceful. That was when I realized that this was the end. It was coming. Whether it be one day or one week.

Mrs. Evans:

So when she came to the home . . . she knew this was it. And it is interesting to me because the doctor didn't know this was it. Doctors never do. The nursing staff didn't know. They were shocked [when she died]. But somehow, I knew. My birthday is March 3. And two days before she died, I took a birthday cake in and we celebrated my birthday, in her room. And again, we went through some papers that she wanted us to go through and her will, you know, she said, "Make sure you know where my will is." And it wasn't in the spirit of "I'm a goner tomorrow," but it was in the spirit of sharing with me and making sure she had those things, she had a sense of closure about those things.

The need for closeness at the end of the mother's life is a reminder that, despite the reversal of roles between mother and daughter and any degree of the mother's dependency on the daughter, the relationship is and remains one between a mother who has raised a child and that child, middle-aged though she may now be. Regardless of daughters' expectations and needs for closeness with and distance from their mothers, care during the terminal period provided one means for daughters and mothers to work out, examine, summarize, and restate key portions of their relationship.

Many accounts suggest that the experience of maternal pain, co-experienced by both mother and daughter, represents the limit for care and for life. The

avoidance of pain is uniformly seen as a goal and a death is frequently labeled as "a good death" when it has been peaceful and pain free, without prolonged disability, struggle, or suffering. As Mrs. Glanville, aged 45, noted, "I didn't want to put my mother through the agony of prolonging life. There's a difference, you know between prolonging life and prolonging death, and the other word for prolonging death, from my standpoint, is torture." Similar thoughts were stated by Mrs. Farkas: "It was painless for her. It was a good way to go. We should all be so lucky."

The Cultural Manner of Parental Death

In general, the narratives disclosed four aspects of the elder parental death experience: the enmeshment of medical care with the story of the death; the occurrence of pervasive ageism, either overtly or covertly, in accounts of the death; difficult or even impossible dilemmas in terminal care of the aged; and the irreducibility of subjectivity in the daughter's biography of her mother, including concerns about the relationship with the mother and her personality. This article has presented some concerns and issues of some middle-aged daughters who told the stories of their mothers' deaths. The stories were often eloquent, moving, and powerful, representing the daughters' strivings toward love, care, and connection for a person who was physically dying. These daughters emphasized that, for them, the death was physical; it was not a social death. These stories often indicate a merged subjectivity as the daughters took on a moral responsibility for their mothers' well-being and for the interpretation and facticity of medical information.

Themes of both ageism and the complexity and futility of treatment run through these narratives. Certainly, much has been made of the difference in perspectives between biomedicine and its goals and people and their goals (Anderson and Bury 1988; Kaufman 1988a, 1988b; Kleinman 1988). Clearly, there is a tension between the medical ideology and its aims of rehabilitation and cure and a native model of recovery and normalcy (Kaufman 1988b).

Yet relatively little attention has been paid to the role of advanced age in this distinction, an absence that itself is perhaps indicative of an underlying ageism. Defining normalcy in old age and at the end of life is problematic and ambiguous. It is true that biomedicine powerfully organizes a compelling system of treatment that is often at odds with the experiential world of people, and that this opposition can be magnified by the ageism and uncertainty at the end of life.

Thus it is not merely the conflict between biomedicine and the experience of people that is in operation here; ageism is operating as well. The clinical participants in the medical events these narratives present often axiomatically assume that the elder is "less than" a full person (because they are old or near death) and should be excepted from the concerns and considerations provided to the young or those at midlife. Ageism is magnified in clinical practice because of the immediacy of the calculus of human value in this field: there is confusion over whether old people are people worth the effort because they will be dead soon and over what to do for them. Of course, it is likely that value-laden attitudes toward the elderly in part precede treatment and the making of clinical decisions and are generalized throughout clinical practice. Further, ageism is magnified here because of the widespread cultural conflation of aging, disease, and decline, so that aging itself is believed to

be a disease and is often used as a diagnostic category (Sankar 1984). Whatever ageist attitudes the daughters in this study may experience in general are diminished in these tales because of the daughter's perception of the mother—even if old, sick, or senile—as a full person, as sharing biography, and as an object of profound moral responsibility.

Finally, the effects of ageism are refracted within the context of the procedural confusion of medicine at the end of a long life. The end of life for the old—and the old and sick—is clearly a contested domain containing conflicting systems of belief and procedure. Issues such as the nearness and the setting for death, the fragmented state of medical care, lack of appropriate medical guidelines for the old, questions about heroic means and the value of life, conflicted families and family agendas, and many other factors combine with pervasive ageist attitudes to produce a deep uncertainty.

Aspects of this confusion are left for the survivors to sort out. The narratives broadly indicate the daughters' interest in working out the details of the medical decline and the mothers' and daughters' own interconnected subjectivities. The stories reported here suggest that these two dimensions of narrative work are not clearly demarcated. While narrators mark the experiential trajectory of decline with an objectively oriented account of medical events, such an enumeration is counterpoint to an inseparable, yet unmergeable, story of cosubjectivity, emotional life, heightened awareness, familial and social constructions of medical facticity, and other such events.

Thus the dilemma of geriatric medical care and pervasive medical ageism heighten these experiential uncertainties. When it occurs, ageism in medicine can permit diminished standards of diagnosis and treatment because the elderly patient can be seen as somehow "less" or not quite a full person, perhaps even as already half-dead. The dilemmas of geriatric medical care concern the certainty of what is correct, proper, and useful in treatment. The negative experiences that can typify modern medicine and that in other circumstances might not merit any comment are widely portrayed as episodes in the "story of the death" largely because they pass through the poorly bounded edge of the mother and daughter's cosubjectivity. They are viewed as wounding to the integrity of the mother and often to that of the daughter.

NOTES

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