The Quality of the Last Year of Life of Older Persons

M. POWELL LAWTON, MIRIAM MOSS, and ALLEN GLICKSMAN

Philadelphia Geriatric Center

THE LAST YEAR OF LIFE HAS RECENTLY COMMANDED the attention of health care planners. Twenty-eight percent of Medicare costs for all enrollees was expended for care during the last year of life, an average annual per person cost of \$4,527 as compared to \$729 for surviving enrollees in 1978 (Lubitz and Prihoda 1984). Nothing is so effective as a threat to the pocketbook in summoning the resources of economists, policy makers, and public officials to seek a solution to a problem. Thus, we have the cap placed on acute hospital length of stay through the diagnosis-related group (DRG) Medicare reimbursement formula, the intensive exploration of the hospice as a substitute for some of the most expensive hospital days (Mor 1987), and, no doubt, many other cost-abatement ventures yet to come.

The driving force behind the recent scrutiny of the last year of life has thus been economic. Hospice (Mor 1987; Morris et al. 1986) and cancer research (Mulhern et al. 1989; Schipper & Levitt 1985) have addressed the problem of the quality of life experienced by dying persons and their families in the last days and weeks of life. Little attention has been paid, however, to the quality of community-resident older people's entire last year of life. Most research on the end of life has begun

The Milbank Quarterly, Vol. 68, No. 1, 1990

^{© 1990} Milbank Memorial Fund

to study the person at the time when death was seen as inevitable or likely. For example, in the National Hospice Study of quality of life, all participants had to have an estimated remaining life of less than six months; about three-quarters were available for study only during the last 3 weeks of their life (Morris et al. 1986). Much less frequent have been attempts to document the course of daily life, events, and health over a standard period of time concluding with but not limited to the final illness and death. Much of all we know about this process has been gained from the study of hospital or nursing-home patients and has dealt primarily with pain and distress or with quality of consciousness (Exton-Smith 1961; Hinton 1963; Kastenbaum 1967; Osler 1904; Weisman and Kastenbaum 1968). The National Institute on Aging's study of "the last days of life," not yet fully reported, was concerned most with the immediate circumstances of death, rather than with the year as a whole or with its quality (Brock and Foley 1985). By far the most extensive study of the last year of life was performed by Cartwright, Hockey, and Anderson (1973), who studied a random sample of 785 persons aged 15 and over in England and Wales, of whom 70 percent were aged 65 or older. This study ascertained the length of illness and disability before death, pain and distress, and other symptoms. Its focus was primarily on the quality of health and welfare services for the terminally ill rather than their quality of life per se. A stream of research on quality of life has emerged, however, from concern over life prolongation, specifically ethical and economic questions that have arisen regarding the combination of high cost of terminal care and subjective distress related both to the illness itself and to the treatments applied. The emphasis in this area has been only on the terminal period and on cancer more than other causes of death (Katz 1987; Mulhern et al. 1989; Schipper and Levitt 1985).

The ethical issues and the concerns of cancer researchers, in particular, have had the fortunate effect of introducing the notion of quality of life into medical research. The Katz (1987) collection of papers on quality of life in chronic illness contained many suggestions for defining quality of life, as have other reports dealing with other contexts (Lehman 1988). The measures vary greatly in both content, theoretical basis, and methodological sophistication. There is clearly a need to fortify the definition of quality of life in both conceptual and empirical terms. The broader relevance of quality of life can facilitate our understanding the varieties of death trajectories.

Goals of the Research

The first aim of the research to be reported, therefore, was to examine the quality of the entire last year of life in a heterogeneous older group of community residents. Because the majority of all deaths occur to persons who are living in the community, and earlier research did deal with institutionalized people (Exton-Smith 1961; Kastenbaum 1967; Weisman and Kastenbaum 1968), the latter group was excluded from this study.

The second aim was to compare the quality of life in the last year with that of an ordinary year of life among living older people. Thus, a community-resident comparison group selected by criteria unrelated to health was studied as well.

The final aim was to portray the changes that occur over the year and the trajectories that different facets of life quality follow as death approaches. In particular, we offer an approach that assesses the quality of the last year in terms of "quality months," a yardstick for use in discussion of values in life prolongation and other policy and ethical issues. This research broadens the population, the illnesses, and the time interval studied in hospice research (Morris et al. 1986). Depicting the positive and negative aspects of the last year of life is seen as vital in order to personalize the "cases" that constitute the data of cost-of-care reports. This report will thus complement the portrait of the last year which focuses on dollars and hospital days by portraying its more personally meaningful features.

The Conceptual Background for the Research

A theoretical model of "the good life" (Lawton 1983) attempts to account for every aspect of life that can be evaluated objectively (sectors of behavioral competence and external environment) or subjectively (sectors of perceived quality of life and psychological well-being). The model further specifies the content of the sectors capable of being measured. There is no presumption of measuring, or even naming, every attribute capable of being evaluated. Rather the structure explicates how attributes should be categorized, how they may be related to each other, and where gaps in measurement capability lie. The sector of behavioral competence, for example, includes domains of biological health, functional health, cognition, time use, and social behavior. Examples of specific measures within these domains are medical diagnosis, mental status score, activities of daily living, and social interaction count. The perceived quality-of-life sector may have cognate domains for every competence domain: for example, satisfaction with health, satisfaction with leisure time, or satisfaction with friends. Environment and psychological well-being have less well-articulated internal structures. The sectors of the good life are related to one another but each also has a substantial degree of independence from one another. Therefore, functioning in any sector or domain may be evaluated without necessarily expecting that the quality of one will be related to the quality of another.

The concept of the good life suggests the attributes and possible measures that might give the most comprehensive picture of the quality of the last year. This conception is consistent with the breadth of the World Health Organization (1948) definition of health as "a state of complete physical, mental, and social well-being."

Method

The subjects for this study were chosen by sampling city death records and locating the person named as the closest surviving relative who was to be interviewed regarding the quality of life of the deceased person. A random sampling by month of the approximately 24,000 death records in the city of Philadelphia across a 12-month period beginning November 1982 yielded 1,048 death certificates. Each was then subjected to further screening in terms of the following criteria: age 65 and over, residence within the city, the naming on the death certificate of an informant who could have been in close touch with the deceased during the last year of life, residence in the community rather than a residential institution at the time of death, and less than 3 months of consecutive-days' residence in an acute hospital during the last 3 months of life. Information not on the death certificate was obtained from a first telephone screening with an informant. Almost one-half (49 percent) were considered ineligible from examination of the death certificates, primarily due to age (40 percent under the age of 65) or to not having lived in Philadelphia prior to their death (6 percent). Of the 534 records of Philadelphia residents aged 65 and over who initially appeared not to be residents of institutions, 76.8 percent were found to be eligible by all criteria, while 10.5 percent were ineligible because further inquiry indicated that the decedent had been in a nursing home or other institution and 12.7 percent were ineligible because no local closest relative was listed or could be contacted. The base number of eligibles was 410. These people's survivors were contacted; 51.2 percent of the informants refused or failed to complete an interview, and 48.8 percent, or 200, were successfully interviewed.

It is clear that the final group whose deaths were represented was a more residentially stable and (during their last months) healthier (i.e., less likely to have required long hospital or institutional care) group of older people than the universe of people aged 65 and over who died during that period. The bias introduced by the high rate of refusals is more difficult to characterize. Comparison of death-certificate data for refusers and the successfully interviewed revealed no significant differences in age, cause of death, occupational prestige rating, place of birth, or place of death. Men, whites, and spouse survivors, however, were significantly more likely to refuse the interview. Thus, the total estimates for people in their last year of life must be interpreted in light of the deliberate exclusion of the institutionalized and a comparative under-representation of white females who were married at the time of their death (there were 4 of these in the group in their last year of life as compared to 17 in the community group to be described later). In summary, the subjects were residents of Philadelphia over the age of 65 who were not living in a nursing home at the time of death and whose surviving kin was willing to report retrospectively on the older person's last year of life.

The comparison group (referred to hereafter as the community group or the ordinary-year group) was composed to match three basic background characteristics of the group in their last year of life (LYOL): age (within the appropriate age category: 65-70, 71-79, 80+), sex, and geographic area of residence. The interviewer started at the former residence of the deceased person and went systematically door to door in one direction from that structure seeking a person of the same age and sex as the deceased. In order to maintain methodological comparability with the LYOL group, it was necessary to interview an informant about the still-living targeted older person, rather than to gather the data from the sampled living older person herself. Permission to be in the study thus had to be obtained first from the sampled older person, who then had to nominate the informant, who in turn had to be willing to be interviewed. The informant selected was the person who could tell us most about the targeted older person during the past 12 months: that is, about health, daily activities, and attitudes.

Available funds allowed a sample of 150 living older persons to be compared with LYOL decedents. From the 200 LYOL decedents 150 were randomly selected to be matched with a living older person. To obtain this number of completed interviews, contacts were attempted in 2,407 households, of which 40 percent had no one at home, 5 percent refused or were otherwise not able to be screened, 46 percent had no person aged 65 or over, and 9 percent were screened. Of those screened who were in the eligible sex/age cohort (157), only 4 percent refused to participate.

Table 1 records the background characteristics of the two groups. As would be expected because deceased people were sampled, the mean age of 77 was higher than that for people in general 65 and over. Other background characteristics were what one might expect for people of that age living in Philadelphia. It is of particular interest that the character-

Background characteristics	Last year of life $(N = 200)$	$\begin{array}{l} \text{Community} \\ (N = 150) \end{array}$
Female	54%	57%
Marital status	36%	43%
White	66%	67%
Mean age (S.D.)	77.4 (7.9)	77.0 (7.7)
Protestant	43%	45%
Catholic	37%	41%
lewish	13%	11%
Income (single person) (S.D.)	\$6,180 (\$2,979)	\$6,180 (\$3,271)
Mean years' education (S.D.)	9.4 (3.5)	8.4 (3.2)
Relation of informant to deceased person		
Spouse	28%	37%
Child	44%	21%
Other	28%	42%

TABLE 1 Background Characteristics of Last Year of Life Subjects and Community Subjects

istics of the targeted older person that were not the basis for matching (race, marital status, religion, income, and education) were as similar between the two groups as were the matching characteristics (chi squares not significant). There were substantial differences between the LYOL and community groups in the relation of the informant to the targeted older person: The LYOL group included proportionately fewer spouses, more adult children, and fewer other types of relationship (chi square = $20.7, 2 \, df, p < .01$). Thus, the high refusal rate among survivors and the low refusal rate among community residents resulted in a final difference between the LYOL and community informants only in their relation to the targeted person. The consequences of this difference in relationship need to be explored in future analyses of the relations between type of informant and reported decedent data.

Unquestionably a limiting factor on generalizability even more potent than those related to sampling is the fallibility and active distortion introduced by having an informant as the source of data rather than the older person.

In most of the cancer quality-of-life studies (Katz 1987) the sources of the data were variously the subject, a family informant, or a professional, with no direct analyses of the validity of the ratings or agreement among multiple sources. This potential error must be borne in mind at every step. On the other hand, living with this limitation allows this first look at a great variety of life-style indicators that could be ascertained first hand only by a prohibitively expensive prospective study. Such a study would require a costly sampling procedure to begin with and the intensive study over two years of more than 4,000 older people to yield a comparable-sized sample of people whose last year was documented. Thus, we offer a first-cut estimate in the hope that future research may ultimately provide more firmly generalizable findings.

Full discussion of the validity issue requires an extended report in its own right. Information on validity was possible to obtain for some variables. Three approaches to estimation of validity were used. First, for 23 deceased people, a closest-of-kin informant and a second informant with knowledge of the person's recent life were interviewed independently. Second, for 18 living older people, extended interviews were performed both with the closest-kin informant and the older person. Third, for 105 living older people, a short set of basic self-ratings of their own quality of life were obtained to compare with similar ratings made by their closest-of-kin proxy respondents. For the largest sample (n = 105), exact agreement was achieved for 62 percent of 4-point ratings of pep and energy; 68 percent of 4-point ratings of pain; 60 percent of 5-point ratings of memory; 52 percent of 5-point ratings of depression; and 81 percent of 3-point ratings of independence in work around the house, i.e., activities of daily living (ADL). Agreement levels within one point ranged from 84 percent to 96 percent. The percentages of agreement were comparable to those just cited for most of the variables on the longer interview completed by 18 pairs of informant and living older person raters and the 23 instances of ratings by two survivors. The two smaller reliability samples contained some missing data and, together with their small size, did not afford stable estimates of kappa. For the 105 subject sample, the kappas ranged from .07 to .76, median = .44. While such levels of agreement are lower than might be acceptable for many purposes, the demands on the rater for retrospective ratings of attributes that even at best are difficult to assess are extreme. The conclusion must be that caution is appropriate in interpreting the results; the error is likely to have attenuated, however, rather than enhanced, the sizes of various relationships (Andrews 1984).

The group that was studied differed from the universe of deaths in the United States. In the pre-Medicare year of 1961, 17 percent of all deaths of people aged 65 and over occurred among institutionalized people (National Center for Health Statistics 1966). In 1976, and again in 1985, the figure was about 22 percent (Sager et al. 1989, 126). These nursing-home deaths were unrepresented in our sample by design because the literature has dealt with institutional deaths better than with the deaths of people still living in the community. Over the year, 84 percent of LYOL subjects, compared with 27.7 percent of community subjects, spent one or more days in the hospital. At 3 months before the target date (date of death or date of interview regarding a living person), 9 percent of LYOL and 6.1 percent of community subjects were hospitalized. At one month corresponding figures were 25 percent and 2.0 percent. Hospitalization time was thus clustered in the extreme terminal period.

Procedure

The person listed in the death certificate was initially contacted by mail 6 months following the relative's death. This interval was chosen to

balance the need for a time for the survivor to adjust to bereavement with the known effects of memory decay about events and conditions that might have preceded the older person's death. Each surviving informant who agreed was interviewed by one of 4 social scientist research assistants who were college graduates or held masters degrees. The interview was usually done in the informant's home. For the community sample, explanations of the purpose of the study were provided to both older person and informant; field work and interviewing of this group were done by a professional contracted interview team.

The Indicators of Quality of Life. The format for data gathering was the structured interview. Many conceptions of quality of life have been advanced for research in cancer, the hospice, and the chronically mentally ill. The senior author's good-life model was made operational in a set of assessment devices, the Philadelphia Geriatric Center Multilevel Assessment Instrument (MAI) (Lawton et al. 1981). For the present research, measures from the sectors of behavioral competence, perceived quality of life, and psychological well-being were chosen; the fourth sector, objective environment, was not assessed because of the much-increased interview time that such an assessment would have demanded. A sampling of domains from the three sectors was made in order to represent aspects of life quality that would be especially germane to the last year.

Some domains were assessed by standardized, closed-ended questions posed during the interview. Eighteen major indicators of the good life were used. Ratings were obtained by asking the informant to rate each characteristic 12 months before death, 3 months before death, and 1 month before death. Single-item rating scales were used for most of the quality-of-life indicators in preference to the MAI multi-item measures in order to simplify the task for the respondent and to reduce interview time. After obtaining ratings for these 3 time periods, LYOL subjects were shown a time line with these ratings plotted on it and were asked to fill in ratings for the remaining intervening 9 months, an approach that seemed to make it easier to reconstruct the month-tomonth picture. In the case of the still living, the times were 12 months ago, 3 months ago, and "now," without the intervening months. Other questions inquired about the year in general or specific time spans within the year. Although considerable fluctuation could, and sometimes did, occur between the 12- and 3-month and the 3- and 1-month intervals, most LYOL informants reported linear progression between 2 points.

	Scale		Last year			Ordinary year	
	tange ^a	12 mo.	3 mo.	1 mo.	12 mo.	3 то.	Now
I. Behavioral competence							
1. Health							
Activities of daily living ^b							
Eating	1-3	2.83	2.70	2.34	2.88	2.86	2.88
Walking	1-3	2.68	2.53	2.22	2.81	2.76	2.79
Bathing	1-3	2.59	2.33	2.01	2.79	2.75	2.77
Laundry	1-3	2.21	1.94	1.67	2.48	2.39	2.42
Transportation	1-3	2.43	2.16	1.92	2.56	2.45	2.49
Shopping	1-3	2.14	1.80	1.58	2.39	2.31	2.34
Housework	1-3	2.14	1.85	1.61	2.40	2.29	2.31
Pep, energy ^c	1-4	2.94	2.40	2.06	3.24	2.95	2.92
Pain, physical discomfort	1-4	2.81	2.51	2.29	3,16	3.11	3.07
2. Cognition							
Mental clarity	1-5	4.59	4.40	4.25	4.70	4.66	4.64
Memory	1-5	4.22	4.02	3.91	4.17	4.13	4.05

TABLE 2 Domains and Indicators of Quality of Life

10

M.P. Lawton, M. Moss, and A. Glicksman

3. Social behavior								
S visits relatives	Freq. code	1-6	2.21	1.89	1.65	2.43	2.33	2.34
S visits friends	Freq. code	1-6	2.50	2.13	1.85	2.62	2.53	2.61
Relatives visit S	Freq. code	1-6	3.56	3.62	3.77	3.29	3.24	3.26
Friends visit S	Freq. code	1-6	2.90	2.81	2.83	2.93	2.89	2.93
II. Perceived quality of life								
Satisfaction with t	time use	1-5	3.92	3.63	3.37	4.15	4.07	4.05
III. Psychological well-being								
Depression		1-5	3.52	3.27	3.11	3.88	3.78	3.89
Interest in others	& world	1-4	3.33	3.06	2.77	3.29	3.24	3.28
N				164			148	
^a High score always denotes favorab ^{b For} ADI all multivariate and uni	ole direction. ivariate tests of arou	time a	d their interact	ion simificant	100 > 4			

For ADL, all multivariate and univariate tests of group, time, and their interaction significant p < .001. ^c For the 11 variables in lower panel, all multivariate tests significant p < .001. All univariate tests significant at p < .01 except all friends visit subject measures and memory LYOL-community difference (ns).

Table 2 records the measures used as quality-of-life indicators for the present report, each rated at the 3 time intervals, and grouped by the 3 sectors of the good life: behavioral competence, perceived quality of life, and psychological well-being. The ADL indices were derived from the MAI (Lawton et al. 1982). The other domains of behavioral competence and all domains in the other two sectors were measured in the rating-scale format.

The social behavior domain of behavioral competence was assessed by the relatively objective index of interaction counts, as done in the MAI and in most social-network research (e.g., Fischer 1982); quality of social contact was not included in these measures. The perceived quality-of-life sector requested judgments of the degree of satisfaction experienced by the deceased person in the domain of time use. The sector of psychological well-being was indexed by 3 ratings: (1) depression; (2) hope (the extent to which the person felt there was something to live for) (see appendix note 1); and (3) "interest in other people and what goes on in the outside world." This latter construct is not a usual member of the psychological well-being domain. Maintaining some extrapersonal orientation seemed to the investigators to be a critical indicator of quality of the last year of life; this rating represented psychological well-being, rather than a domain-specific indicator of perceived quality of life. Monthly ratings were obtained for the LYOL group only (not shown in table 2) of the frequency with which the subject was observed sleeping, resting, or doing nothing during the normal waking day ("null behavior." another index of time use).

Analytic Approach

Because this report is largely descriptive, absolute percentages, twogroup comparisons between last year of life and ordinary-year groups, and multivariate analyses of change within the year were the major analytic strategies.

Results

Physical Health Conditions

Death Certificate Data. Because there are so many sources of error in the cause of death listed on death certificates, only a brief listing of the most prevalent disorder categories (first digit of ICD9 code) will be given here: 90.5 percent of all causes of death were included among 6 disease classes (52.0 percent circulatory; 25.0 percent neoplasm; 5.0 percent respiratory; 3.5 percent digestive; 3.0 percent metabolic; and 2.0 percent infectious diseases).

Health Conditions. The most important difference between the LYOL and ordinary-year groups was in their health status during the targeted year. Table 3 shows the percentages reported for each of the 21 conditions forming the MAI health conditions checklist (Lawton et al. 1982). Any number of conditions could be checked. The differ-

	LYOL	Community	Chi Square
Circulation problems	58%	29%	30.1*
Heart trouble	56	21	45.8*
Arthritis	54	48	1.4
High blood pressure	49	39	3.4
Tumor or cancer	36	6	38.5*
Bladder trouble	27	6	23.3*
Diabetes	27	11	12.4*
Cataracts	26	22	0.8
Other effects of stroke	20	8	8.8*
Kidney trouble	17	5	9.3*
Any paralysis	17	7	6.8*
Pneumonia or flu	16	11	1.2
Liver trouble or jaundice	15	2	14.6*
Emphysema or asthma	14	7	4.0
Anemia	11	7	0.9
Glaucoma	9	7	0.7
Gall bladder trouble	6	1	4.4
Stomach ulcer	6	3	1.1
Other (not hip) broken bones	5	2	1.4
Parkinson's disease	2	3	0.0
Broken hip	1	1	0.0
Ν	200	150	

TABLE 3 Percentage Reporting Health Conditions over Year

* p < .01

ence is clear: In 19 of the 21 conditions, the direction of prevalence rates was greater in the LYOL group, 9 of the differences being individually significant. The difference across the total array was highly significant (Hotelling's $T^2 = 8096$, df = 21,323, F = 36.3, p < .01). Such a major health difference set the stage for expecting lower wellbeing in many areas of life among the LYOL subjects.

Quality of Life in Last Year Compared with an Ordinary Year

Table 2 gives the descriptive data from which both group differences and changes over time were derived, that is, the indicators of wellbeing that were determined at 3 intervals for both groups. Data shown in the upper and the lower panels of table 2 were analyzed by multivariate analysis of variance (MANOVA). An alpha level of .01 was used for the multivariate test (Wilks's lambda, an estimate of the proportion of variance not accounted for by the independent variable) and .05 for univariate tests when the overall effect was significant.

The upper panel shows the means of the separate tasks that compose the 7 physical and the instrumental activities of daily living. Data from the same ratings are represented graphically in figure 1. The MANOVA compared the LYOL with the ordinary-year group across 3 occasions (see appendix note 2). Differential change by group was tested in the interaction term.

There were significantly (p < .001) greater ADL deficits in the LYOL compared with the community group (Wilks's lambda .87, F = 7.17, df = 7.333), increasing impairment across time (Wilks's lambda .80, F = 11.58, df = 14,1344), and increasing impairment in the LYOL group over time compared with the community group (for the interaction Wilks's lambda = .84, F = 8.97, df = 14,1344). Every univariate test among all these comparisons was also significant p < .001.

Similarly, the other indicators of well-being are shown in the lower portion of table 2; for clarity of presentation, only selected indicators from table 2 (alertness, interest in world, depression, and subject visits friends) are shown in figure 2. Another MANOVA was done in similar fashion among all 11 of the indicators shown in the lower panel of table 2.

The LYOL group also showed overall lower quality among the indicators in the lower panel of table 2 than did community subjects



FIG 1. Activities of daily living for LYOL and ordinary-year subjects at three retrospective time intervals.

(Wilks's lambda = .82, F = 5.96, df = 11,300, p < .001). The groups did not differ in the univariate comparisons of memory or frequency of friends' visits to the older person, but all other group differences were significant. The frequency of family visits to the older person was greater in LYOL, however, compared with community subjects in the univariate comparison (F = 4.79, df = 1,310, p < .05). There was also a significant multivariate decline in quality of life over time (Wilks's lambda .69, F = 11.52, df = 22,1220, p < .001). This time-related decline was seen in univariate tests as well, with the exceptions that there was no time-related change for frequency of friends' visits and there was an increase in frequency of family visits (F = 5.34, df =2,309, p < .01). The multivariate interactions between group and time were also highly significant (Wilks's lambda .86, F = 4.42, df =22,1220, p < .001). The univariate interactions again showed the



FIG 2. Indices of quality of life for LYOL and ordinary-year subjects at three retrospective time intervals.

LYOL group to have become selectively more impaired over time compared with community subjects except for frequency of friends visiting, which remained constant for both LYOL and community groups, and frequency of family visits, which increased selectively among the LYOL subjects (F = 6.76, df = 2,309, p < .01).

In summary, the results revealed that even one year before death, the LYOL group began with lower levels of competence and well-being than did the ordinary-year group. The trajectory was clearly downward in the LYOL group for the indicators of functional health. A downward trend, though not as marked, also characterized most of the other indicators: energy, pain, mental clarity, satisfaction with time use, going to visit family and friends, depression, and interest in world. Not only were these absolute declines, but the declines were significantly greater among LYOL subjects relative to ordinary year subjects. Notably different from the above were an unchanged rate of being visited by friends and an increase in rate of being visited by relatives.

Stability and Change during the Last Year

Analysis of central tendencies made it difficult to understand the total picture of level, stability, and change. The last aim of the research was to provide descriptive information on what changes occurred with what frequency. The change data were converted into a ledger of the positive and negative features as accumulated over the year.

Types of Stability and Change. It is worth mentioning first that our arbitrary choice of one year as the interval by which to define the last period of life did not fully capture what might be thought of as the total winding down. Informants were asked to estimate when the decedent "first really began to go downhill." The median period of decline was 14 months. Thus, somewhat more than one-half of our subjects had begun to exhibit some decline before the reference year began. Figures 3 through 6 depict more clearly selected rated indicators of well-being at their beginning level and the proportions that moved

"How much of the time did (she) seem to be feeling pain or physical discomfort:"



FIG 3. Pain: Direction of change over last year of life.

"How much of the time was (name) completely mentally clear, that is, how much of the time did (she) know what was goir 3 on around (her), know where (she) was, and the day of the week and the season:"



FIG 4. Mental clarity: Direction of change over last year of life.

in different directions over the course of the year. Totals do not add to 100 percent because of rounding errors and "don't know" responses at later times. The width of the black arrows represents the proportions in each category. The figures were selected from among the 11 such possible figures to represent the major facets of quality of life as well as those that changed in differing degrees over the year. It should be noted that the rating at 12 months for some of the sample represented a lifelong level of some attributes, for others a long-term though reduced level from some higher earlier level, and for some a more recent impaired level related to the cause of death.

Figure 3 depicts the course of pain over the year. Although onequarter maintained a minimal (never or seldom) problem with pain throughout the year, 38 percent had unremitting (frequent or all the



"How often was (name) depressed:"

FIG 5. Depression: Direction of change over last year of life.

time) pain and the course was toward increased pain for 51 percent. By the last month a small number of informants (5 percent) were unable to judge pain due to reduced levels of consciousness.

In contradiction to lay views of the end of life as an inevitably confused and cognitively impaired period, the trajectory of mental clarity (figure 4) mainly was one of stability, with 66 percent being alert all or most of the time throughout the year. About one-quarter (27 percent) declined substantially or remained low in alertness through the year. Depression (figure 5) did increase for 29 percent but remained constant at a low level (never or seldom) for 41 percent.

Visiting by family members (figure 6) was generally stable (65 per-



"How often did relatives come to see (her)?"

FIG 6. Frequency of relatives' visits: Direction of change over last year of life.

cent) from 12 months to 1 month before death with a clear excess of increased over decreased frequency across the entire year including the last month. However, 24 percent had a stable low frequency of visitation (less than once a month or never).

A Ledger of the Last Year's Quality: The Quality Month. The lack of a true yardstick is a problem that besets every study of the quality of life. An attempt was made with the present data to summarize the 12month picture of overall quality. Providing a quality-of-life ledger across all the domains required a number of simplifying assumptions. First, a short list of salient domains was required. Choosing such a list was dictated first by Lawton's (1983) good-life structure; at the same time, the domains included all 6 of those used by Spitzer et al. (1981) and they overlapped substantially with those used by Morris et al. (1986). Within domains, we avoided weighting any one area more heavily than others; for example, although table 2 shows 4 separate domains of social interaction, the quality-of-life ledger reduced these by a simple sum to a single domain of objective social behavior.

A second assumption was that all domains in the ledger were equally important. The intrinsic lack of an ultimate external criterion of overall quality of life forces one either to equate all criteria in importance or subject them to consensual judgments of differential importance; this latter exercise seems likely to be singularly unproductive, since relative importance is so much an individual difference characteristic.

The third assumption was that each domain may be scaled in such a way that a particular score separates high from low quality. There are obvious problems in each of these assumptions. We offer the analysis to follow as a starting point from which later research may proceed to make improvements.

The ledger was derived using as a basic unit the "high-quality month," that is, a month during which a person experienced a good quality of life in a particular domain (see appendix note 3). The definitions of high quality in each domain were:

- Pain: Seldom (mild) or never
- Alertness: Mentally clear all the time or most of the time
- ADL: No help at all or less than once a week
- Social: Average contact frequency (family and friends) 1 to 3 times per month or more (see appendix note 4)
- Time use: Five hours or less per waking day spent napping or doing nothing
- Satisfaction with time use: Satisfied with way spends time always or most of the time
- Depression: Seldom or never depressed
- Interest in the world: Somewhat or very much interested
- Hope: Felt somewhat or very much that there was something to live for

Each month of a subject's last year was characterized either as of positive or negative quality by the score on each of the 9 domains. Table 4

	Life
	Ę.
	JS 6
	nt
	Мo
	Ve
	[Me
	st]
	La
	the
	OSS .
	acr
	ins
	ma
	å
	line
	Z c
4	ty.
BLE	ilali
Ł	õ
	tive
	osi
	ച്ച
	rcin.
	rien
	per
	Ð
	as
	Ited
	Ra
	nts
	ede
	Dec
	of 1
	cs (
	Itag
	Icer
	Pei

					Satisfaction					F
Month	Pain	Alert	ADL	Social	with time use	Null behavior	Depression	Interest	Hope	+ QOL%*
12	63%	91%	71%	74%	82%	84%	73%	79%	89%	84.7%
11	62	90	67	74	81	84	73	78	89	83.7
10	60	88	<u>66</u>	74	81	83	73	78	89	83.7
6	60	88	67	74	81	82	74	76	87	82.2
œ	60	86	68	73	80	83	73	75	86	81.6
2	60	86	67	73	79	82	72	75	86	81.7
9	58	85	65	71	79	81	72	73	85	81.2
Ś	57	83	64	71	77	81	71	71	84	80.1
4	50	81	59	70	73	79	69	69	81	78.5
ŝ	49	79	55	67	72	76	65	66	80	74.9
7	45	74	50	67	69	67	62	60	77	68.1
1	42	73	42	67	64	60	62	57	74	64.9

* Percentage of subjects with positive quality in 5 or more domains.

records the percentages in each domain who were classified in the positive-quality range for each of the 12 months. For these percentages, all valid data were used, so the amount of missing data is small. The familiar downward trend is obvious. By the 4th month before death onehalf exhibited negative OOL in the pain domain, while in the ADL domain that point was reached 2 months before death. Otherwise, even down to the final month the majority of subjects were in the positive range. The last column of table 4 records a summary across domains by counting a month as positive for a subject if 5 or more of the 9 domains were rated as positive. This classification principle was chosen a priori as a simple majority of domains; a criterion of 6 out of 9 would be equally defensible, but when used it, of course, resulted in a reduction of percentages showing high quality of life. This QOL ledger began as strongly positive in month 12 (84.7 percent with a majority of positive QOL domains) and even by month 1 almost two-thirds (64.9 percent) showed this positive balance.

The average subject experienced 77 out of the 108 possible positive units during the last year of life. Only 18.4 percent experienced fewer than one-half of the monthly units as high quality.

Discussion

The discussion will consider the meaning of the results of the current study in terms of what it adds to our knowledge of the process of dying. The light shed by this research on some of the more general social problems surrounding longevity will be discussed.

Bias in Retrospect

The discussion must begin by acknowledging once more the possible sources of error in the data, whether from limitations in the informant's knowledge of the deceased person's life, memory decay over time, or bias in reporting. The data tell little about possible bias. Lopata (1973) has discussed "sanctification" of the deceased spouse as one mode of responding to widowhood. In the present study a minority of informants were the widowed spouse (37 percent). Did survivors sugarcoat their reports in defense against their guilt or because of a wish not to acknowledge the depth of their relatives' distress? The data do not answer this question, except that recent anthropological studies of surviving relatives in a care-giving history study have found people eager to share their negative as well as positive reports of the end of their loved one's lives (Rubinstein 1989). Future research will do well, however, to explore explicitly whether, in what direction, and with what correlates, biased retrospection occurs.

How Bad Is the Last Year of Life?

The data presented in this report are very clear in showing the lowered quality of life in its last year compared with a random year picked out among currently living older people. Omitting the nearly 25 percent of all deaths of older people that occur in nursing homes resulted in the omission of a year of probable great debilitation for these people. It is thus possible that we also overrepresented the quality of the last year. It is not self-evident that the quality of the last year is worse in the nursing home, however. Rather, that is another question requiring necessary answers through additional empirical research. Space also limits including such interesting questions as the effect of different causes of death on quality of the last year; variations attributable to the marital status of the decedent or the informant's relationship to the deceased; and the household membership of the surviving informant.

Despite the decrement in overall quality, there were virtually no indicators that pointed to an overall negative picture for the majority of people over the entire year. Although instrumental behaviors were the most compromised (fewer than one-half maintained full independence by 3 months before death), the self-care tasks that most clearly mark the person as still self-directing (eating, bathing, and ambulation) were well above this level. Mental alertness was only moderately affected; although memory was rated as declining substantially, the ending level in the group that died was not significantly different from the presentrated memory of the still-living. Depression was considerably more prevalent in the last year than in the ordinary year, yet one-half of those who were in the terminal group were considered not at all depressed up to 3 months before death. Even more telling was the opinion by 45.5 percent of the informants that their relative felt there was "a great deal" to live for just one month before death. Finally, family visits increased and interest in the outside world declined only a small amount.

It can be concluded that the end of life has a substantial component

of life as it always was. The generally parallel course of psychological or behavioral frailty with the course of physical health only affirms the truism that the healthy are happier. Yet, incursions on quality of life were substantially less pervasive than would be inferred from knowledge about physical health alone.

Social Policy and the End of Life

There have been many ethical, economic, and social-value discussions of issues surrounding the end of life. This report cannot attempt to do justice to such complex questions. The results of this research provide useful additions to the body of knowledge attesting to both the measurability of quality of life and the central position that individual and aggregated quality of life should play in debates regarding prolongation of life, treatment priorities, and societal health care costs, to name only a few.

The present research speaks to some assertions that the ending period is totally negative. Estimates that 24 percent were in a low level of consciousness at some point during the last year, that 38 percent were not always alert by the last month, and that 66 percent suffered from substantial pain during the last month of life are negative facts. One must compare these percentages with their complements one month before life ends and the aggregate of better quality experienced in the preceding 11 months. The concept of high-quality months accreted across all domains of life quality may be a yardstick by which the goodness of life may be measured. The conclusion from this research that 81.6 percent of the community-resident decedents experienced a majority of high-quality months represents a first estimate of overall quality of the last years of life. Future research should replicate this estimate using different yardsticks and different populations.

We have heard for a long time "Add life to years, not years to life" (adopted as a journal slogan of the Gerontological Society of America in 1948). To make that definition of "life" operational means, first, looking comprehensively at the attributes that make life good: self-care independence, cognitive skill, and all the other indicators examined here. The research was not designed to test the good-life model. The model did guide the choice of indicators of quality of life. They were related to one another, but still independent enough to afford meaningfully different profiles of quality for different people. The definition of "life" also means looking at both positive and negative indicators over time, on the theory, for example, that if there are 11 months of alertness in the last year, the quality balance is 11:1 even if the last month is spent in mental confusion. The broad definition of "life" also demands a subjective perspective as a necessary component of quality of life: Only the person can provide the last word on concepts like satisfaction, enjoyment, or pain. By contrast, the objective perspective is necessary to define behavioral competence as an aspect of quality of life. A final consideration is that the data indicating quality of life were contributed to partly by the individual's family or closest other's experience of the dying person. Such data thus confound the family's experience and that of the person; we need to search for methods that measure each separately.

In conclusion, we suggest that individual scores on measures of the type presented here, in improved form, be used to represent the specifics of the individuals who are discussed as statistical or philosophical abstractions. Continued research in this vein should be directed at people who receive greater amounts of life-maintaining care than most of those in our sample. The contribution of our research reported here is to underline particularly the concept that quality of life is multifaceted, distributed over time, partly subjective, and partly objective.

References

- Andrews, F.M. 1984. Construct Validity and Error Components of Survey Measures: A Structural Modeling Approach. *Public Opinion Quarterly* 48:409-42.
- Brock, D.B., and D.J. Foley. 1985. A Survey of the Last Days of Life: Methodology Considerations and Pretest Results. Proceedings of the American Statistical Association, Social Statistics Section, 316-21.
- Carp, F. 1966. A Future for the Aged. Austin Tx: University of Texas Press.
- Cartwright, A., L. Hockey, and J.L. Anderson. 1973. Life before Death. Boston: Routledge and Kegan Paul.
- Exton-Smith, A.N. 1961. Terminal Illness in the Aged. Lancet 2:305-8.
- Fischer, C.S. 1982. To Dwell among Friends: Personal Networks in Town and City. Chicago: University of Chicago Press.

- Hinton, J.M. 1963. The Physical and Mental Distress of the Dying. Quarterly Journal of Medicine 32:1-21.
- Kastenbaum, R. 1967. The Mental Life of Dying Geriatric Patients. Gerontologist 7:97-100.
- Katz, S. 1987. The Portugal Conference: Measuring Quality of Life and Functional Status in Clinical and Epidemiological Research. *Journal* of Chronic Diseases 40(6):459-650.
- Lawton, M.P. 1983. Environment and Other Determinants of Wellbeing in Older People. *Gerontologist* 23:349-57.
- Lawton, M.P., M. Moss, M. Fulcomer, and M.H. Kleban. 1982. A Research and Service-oriented Multilevel Assessment Instrument. Journal of Gerontology 37:91-99.
- Lehman, A.F. 1988. A Quality of Life Interview for the Chronically Mentally Ill. Evaluation and Program Planning 11:51-62.
- Lopata, H.Z. 1973. Widowhood in an American City. Cambridge, Mass.: Schenkman.
- Lubitz, J., and R. Prihoda. 1984. The Use and Cost of Medicare Services in the Last 2 Years of Life. *Health Care Financing Review* 5:117-31.
- Mor, V. 1987. Hospice Care Systems: Structure, Process, Costs, and Outcome. New York: Springer.
- Morris, J.N., S. Suissa, S. Sherwood, S.M. Wright, and D. Greer. 1986. Last Days: A Study of the Quality of Life of Terminally Ill Cancer Patients. *Journal of Chronic Diseases* 39:47-62.
- Mulhern, R.K., M.E. Horowitz, J. Ochs, A.G. Friedman, F.D. Armstrong, and D. Copland. 1989. Assessment of Quality of Life among Pediatric Patients with Cancer. *Psychological Assessment* 1:130-38.
- National Center for Health Statistics. 1966. Hospitalization in the Last Year of Life. Vital and Health Statistics, series 22, no. 1. Washington.
- Osler, W. 1904. Science and Immortality. Boston: Houghton Mifflin.
- Rubinstein, R. 1989. Themes in the Meaning of Caregiving. Journal of Aging Studies 3:119-38.
- Sager, M.A., D.V. Easterling, D.A. Kindig, and O.W. Anderson. 1989. Changes in the Location of Death after Passage of Medicare's Prospective Payment System. New England Journal of Medicine 320:433-39.
- Schipper, H., and M. Levitt. 1985. Measuring Quality of Life: Risks and Benefits. Cancer Treatment Reports 69:1115-23.
- Spitzer, W.O., A.J. Dobson, J. Hall, E. Chesterman, J. Levi, R. Shepherd, R.N. Battista, and B.R. Cathlove. 1981. Measuring the Quality of Life of Cancer Patients: A Concise QL Index. Journal of Chronic Diseases 34:585-97.

- Weisman, A.D., and R. Kastenbaum. 1968. The Psychological Autopsy: A Study of the Terminal Phase of Life. Community Mental Health Journal, Monograph no. 4.
- World Health Organization. 1948. Constitution of the World Health Organization. Geneva.

Acknowledgment: This paper was supported by grant MH37707 from the National Institute of Mental Health.

Address correspondence to: M. Powell Lawton, Ph.D., Philadelphia Geriatric Center, 5301 Old York Road, Philadelphia, PA 19141.

Appendix Notes

- 1. Hope was not measured for the community group because the meaning of "something to live for" was grossly different for the community subjects.
- 2. Missing data in the LYOL group ranged from none to 10-12 (depression, satisfaction with time use, and pain at one month) and almost none in the community group. The MANOVA was done with listwise deletion, however, which reduced the Ns to 164 LYOL and 148 community subjects. The means in table 2 are based on these reduced numbers.
- 3. Categorical definitions of domain quality and of the quality month were chosen over the more psychometrically defensible z-score sums in order to preserve better the meaning of the components of highquality months. In the absence of external absolute criteria for high or low quality in a domain, the arbitrary designations were made in accordance with the authors' judgments of how much decrement might be tolerable in each domain.
- 4. Since 4 social variables (family and friends, visiting and being visited), each measured with grouped categorical data, had to be included in this measure, the median category (1-3 times per month) was used. Since few people went to visit others as they neared death, this median actually represents a much higher frequency of *being* visited.