

Benchmarking as Everyday Functional Assessment in Stroke Recovery

Jaber F. Gubrium,¹ Maude R. Rittman,² Christine Williams,³
Mary Ellen Young,⁴ and Craig A. Boylstein²

¹Department of Sociology, University of Missouri, Columbia.

²VA Medical Center, Gainesville, Florida.

³School of Nursing, University of Miami, Florida.

⁴Department of Rehabilitation Counseling, University of Florida, Gainesville.

Objectives. Functional assessment in stroke recovery extends beyond formal testing and evaluation. Stroke survivors themselves continuously engage in the process of reckoning their functional capacities as they go about their everyday lives. This process is called *benchmarking*. The aim of this article is to discuss and illustrate how it operates in three areas of experience—self-definition, comorbidity and age, and the tasks of daily life.

Methods. Benchmarking data are drawn from in-depth qualitative interviews with male stroke survivors of various ages and from three ethnic groups (Hispanic, African American, and non-Hispanic White).

Results. The results show that the benchmarking process is evident in all social categories in which survivors fall, but specific kinds of benchmarks may be more prominent in some categories than others.

Discussion. The lessons provided by everyday functional assessment for understanding the stroke experience, as well as directions for further study, are discussed in the conclusion.

STROKE is a leading cause of disability among adults (Fujiura & Rutkowski-Kmitta, 2001). In the United States, for example, more than half of the 730,000 people a year who suffer from a stroke have residual motor deficits. Over the next 50 years, this number will double as the population ages (Stineman, Maislin, Fiedler, & Granger, 1997; Taub, Uswatte, & Pidikiti, 1999). In Australia, approximately 40,000 people each year will have a stroke (Australian Institute of Health & Welfare [AIHW], 1999), a significant proportion of whom will experience permanent disability. The picture is much the same throughout the developed world and poses a health problem of tremendous proportion.

The treatment of stroke centers largely on physical rehabilitation, following clinical guidelines (U.S. Department of Health & Human Resources, 1996). Because progress in recovery from stroke is viewed primarily as a matter of regaining physical functioning, guidelines stress functional assessment, rehabilitation screening, physical rehabilitation and related counseling, and the compensatory management of sensorimotor deficits and impaired mobility. Gains in functioning after stroke relate to the likelihood of spontaneous recovery, to the intensity of rehabilitation therapy, and to the stroke survivor's motivation to regain function.

Research on stroke has focused on biomedical and rehabilitation outcomes (Carr & Shepherd 1982; Davis, Bamford, & Warlow 1989; Üstün, Chatterji, Bickenbach, Trotter, & Saxena, 2001; Wade & Langton, 1987). Little attention has been paid to the stroke recovery experience (cf. Blaxter, 1976; Bury, 1996; Williams, 2001). The exception has been important work on survivors' lived understanding of their disabilities (Becker, 1993, 1997; Becker & Kaufman, 1988, 1995; Doolittle, 1992, 1994; Kaufman 1988a, 1988b, 1988c; Kauf-

man & Becker, 1986), which is discussed in the following section. In particular, the question of how stroke survivors assess physical functioning on their own has been ignored. Here, everyday assessment is foregrounded. Stroke survivors are not only subject to the functional assessment methods of formal rehabilitation, but they continuously reckon physical functioning and progress in recovery as part of the ongoing experience of living with stroke.

This article presents the results of research on functional assessment from the stroke survivor's point of view. Stepping outside of the context of formal functional assessment, it considers the everyday reckoning of those who are experiencing stroke. The study of everyday life is well established and deals with how ordinary subjects construct their experiences as part of the worlds they live in (Douglas, 1970; Holstein & Gubrium, 2003; Weigert, 1981). As far as stroke is concerned, "everyday" refers to stroke survivors' practical assessments of being incapacitated or of making progress in recovery. Functional assessment does not end when stroke survivors leave medical or rehabilitation settings; it is an ongoing part of their orientation to and understanding of their disabilities. They continuously take account of their abilities to function in the world.

We refer to the process of everyday functional assessment as *benchmarking*. It is the ordinary activity of designating and applying criteria for assessing functional capacity. The criteria used are the *benchmarks* or markers. Although this activity and its markers are not operationalized as they are in formal functional assessment, they nonetheless can be systematic and the knowledge produced can be useful to survivors in understanding, on a daily basis, the progress they are making in recovering from their disabilities. As Roth (1963) first

suggested decades ago in relation to his personal experience of recovering from tuberculosis, both patients and professional practitioners mark progress in patients' recovery, each of whose meaning-making activity offers valuable information about the pathways of illness and disease. Contemporaneously, Glaser and Strauss (1968) pointed to the ways that dying patients and others benchmarked patients' progress toward death, noting that progress can have distinct trajectories. The concept of benchmarking as we use it here extends these insights to the recovery experience of stroke survivors, a large and growing population whose disability experience is only beginning to be understood.

Benchmarking is not just a process; it relates to specific markers—kinds of benchmarks—that form alternative bases of comparison. In his study of the experience of tuberculosis, for example, Roth showed how patients formed varied reference points for assessing their progress in recovery. He relied as much on these everyday markers as he took account of medical knowledge for understanding the course of his illness. Accordingly, we present the variety of experiences that the stroke survivors we studied use to mark and, on that basis, assess their functioning.

THE STUDY AND RELATED LITERATURE

The research from which the benchmarking data are taken is an ongoing, multisited, and longitudinal project in which both qualitative and quantitative data are being gathered on the stroke recovery experience. The overall aim of the project is to develop culturally sensitive models of the recovery experience after patients are discharged home from the hospital. It centers on interviews with both survivors and their primary caregivers. The research covers three ethnic groups—Hispanic (Puerto Rican), African American, and non-Hispanic White stroke survivors. The goal is to define and describe recovery trajectories for the three groups.

Study subjects are being drawn from the pool of hospital discharges home from stroke in four locations in Florida, a state that has significant populations of Hispanic, African American, and non-Hispanic White stroke survivors. A sample of 40 pairs of survivors and caregivers are being enrolled from each of these groups. Qualitative data gathering includes in-depth interviews with stroke survivors, more limited interviews with caregivers, and some observation in the home, conducted at three intervals after discharge: 1 month following discharge, at 6 months, and at 12 months. All interviews are being tape recorded and observations are undertaken with the written informed consent of both the survivors and their caregivers. Interviews are being conducted by native-language speakers in both Spanish and English and are being translated and transcribed into English; the English transcriptions are being checked against the tape-recorded interviews for accuracy by native speakers. Research protocols have received the approval of the pertinent institutional review boards.

The interviewing follows an evolving qualitative interview guide. The guide is being revised as data offer the opportunity to form understandings of unforeseen aspects of the recovery experience and to move in new directions suggested by the developing analytic framework. In the main, the interview guide deals with the rhythms of daily living, life before and after the stroke, personal management in public settings, body

and stroke construction, the meaning of life, cultural understandings, and the sense of the future. Interviewers have been instructed to encourage survivors to elaborate on their understandings of the recovery experience.

The larger project from which data discussed in this article are taken is entering the second, 6-month, phase of interviewing. The data already are rich enough to warrant the presentation of findings on benchmarking. The 1-month interviews show that the process of benchmarking is commonplace across varied social categories, including ethnicity and age, for example. This indicates that stroke survivors construct the recovery experience in general, and the meaning of physical functioning in particular, on their own, separate from how this is presented to them by medical and rehabilitation professionals. Survivors' constructions are practical and relate to the contingencies of living with stroke on a daily basis in the home and its environs.

As the research is funded by the U.S. Department of Veterans Affairs, the subject pool is limited to veterans from each ethnic group who participate in the Veterans Affairs (VA) health care system. The result is that these stroke survivors are all males. Although, at first blush, this might seem to be a specialized population and raise the question of generalizability, the data show that the experiential concerns and the recovery assessment process identified in this study parallel findings identified by other qualitative researchers from female and male, chronic illness subject groups (see Albrecht, Fitzpatrick, & Scrimshaw, 2000; Becker, 1997; Bury, 1982; Charmaz, 1991; Greenhalgh 2002). While these researchers have not focused explicitly on stroke benchmarking, other processual features of the chronic illness experience they have identified are evident in the VA interviews. All support the generalizability of the VA findings.

The pioneer qualitative research on the stroke recovery experience was conducted by Becker and Kaufman. The findings they describe indicate that what is being uncovered in the VA project resonates with the lived experience of other respondents. The data of their research, which was titled "Sociocultural Mechanisms of Rehabilitation in Old Age" (Becker & Kaufman 1986), were collected in a 3-year (1983–1986) study of patterns of rehabilitation among 102 stroke patients over the age of 45 who were served by a community hospital. Becker and Kaufman were able to conduct several face to face, open-ended interviews with 64 of the 102 patients and with 50 family members over the course of the poststroke year. The hospital served an ethnically and socioeconomically diverse population. As Kaufman (1988, p. 341) explained, "We wanted to hear what patients and families defined as important during the poststroke year." Interviews covered topics such as perceptions of the stroke event, feelings about disability, recovery, loss, and disruption, and information about self-change and altered relationships.

Their findings present evidence of the everyday construction of the recovery experience. In a discussion that reflects our own material, Becker and Kaufman (1995) noted that survivors assume, more than physicians do, that recovery trajectories are open to manipulation if one works at it. Although survivors often received vague medical responses to concerns over the uncertainties of recovery, they nonetheless constructed certainty on their own in relation to the everyday contingencies of

living with disabilities. Medical vagueness was supplemented by personal meaning-making, in other words, which also is evident in the VA material. In a case study of one respondent from their larger study—a White, 65-year-old woman named Mrs. Green—Kaufman (1988b) discussed the extensive “biographical work” undertaken by the stroke survivor. As we are finding in the VA study, Kaufman pointed out that “the way the ill person comes to terms with loss or change will greatly determine the meaning given to the illness” (p. 218). The case study illustrates that stroke is not something that exists solely as an objective condition in the survivor’s life, but takes on subjective meaning in relation to how self-changes are constructed by the survivor on his or her own. Using the same data set, Becker (1993) pointed out that rehabilitation therapists commonly confound the effects of age with the effects of stroke when relating to stroke survivors. As we show in what follows, the VA material suggests that this extends to survivors’ own explanations of their disabilities, especially to how everyday functional assessment is subjectively benchmarked in relation to age and comorbidities.

Doolittle’s (1990) findings from her study of stroke survivors’ bodily and practical knowledge of coping during recovery also parallel the VA survivor material. Doolittle’s study focused on the process by which survivors evaluate bodily recovery. Over the course of 6 months, she conducted 120 interviews with 13 individuals who had experienced lacunar stroke; 8 of the participants were men and 5 were women. They ranged in age from 50 to 88 years and were of mixed ethnic background: 6 Whites, 4 African Americans, and 3 Filipinos.

Just as Becker and Kaufman found cross-gender and cross-ethnic meaning-making, Doolittle presented meaning-making activity that cuts across these categories. Doolittle’s findings also reflect a number of the broad characteristics of the VA stroke survivors’ experience. As the VA stroke survivors do, Doolittle’s (1992) respondents reported engaging in extensive “body talk” in her interviews, speaking to their bodies, and especially to nonfunctioning limbs, as if they were subjects separate from themselves. They also reported their affected limbs as “talking back” to them. This continuous “conversation” that survivors have with their bodies is part of the process by which they communicate to themselves and to others their understanding of the functional status of affected limbs.

Doolittle’s 1994 study comes closest to describing the benchmarking process. There she reported how her respondents use a variety of metaphors to convey the meaning of their impairment and to mark the horizons of recovery. For example, some speak of the need to place “mind over matter” in order to render their limbs and related functioning reliable (p. 215). What Doolittle called the “work of recovery” is close in conceptualization to benchmarking, both of which refer to the everyday process by which survivors test the functioning of their affected limbs against a variety of practical standards (or benchmarks) in order to derive a sense of where they stand in recovery trajectories.

All told, these qualitative studies suggest that the broad contours of the everyday experience of our sample of VA stroke survivors, although all male and veterans of varied ethnic background, have striking resemblance to those of other stroke survivors, both male and female. This implies that the process we focus on here—benchmarking—operates in terms of the

meaning-making actions of stroke survivors as a whole, in connection with the practical contingencies of everyday life. Of course, there may be differences between men and women, say, in *what* is used to benchmark everyday functioning, an issue to which we return later. In the following sections, we discuss and illustrate from our 1-month interviews three areas of experience that our stroke survivors use to benchmark everyday functioning—self-definition, comorbidity and age, and the tasks of daily life. Each area has a variety of dimensions, which further distinguish the everyday assessment process. In the conclusion, we consider the lessons of everyday functional assessment for understanding the stroke recovery experience, as well as directions for further study.

SELF-DEFINITION AS A BENCHMARK

Although we regularly refer to our respondents as “stroke survivors” and, indeed, they themselves convey their identities in these terms, they also communicate senses of self that go beyond this to specify the meaning of recovery. Time and again, respondents place the challenges of daily functioning in the context of who they figure they were as persons. They are stroke survivors of various kinds, of course, but they also bring distinct senses of who and what they are as individuals to their understanding of physical functioning. Conceptions of what it means to be a stroke survivor relate to the particular kind of person they figure themselves to be. These definitions of self are important benchmarks for assessing everyday functioning.

In their own words, respondents typically benchmark their functioning in this regard by referring to “the sort of person I am.” Depending on this self-definition, weakened or paralyzed limbs are more or less dysfunctional for them. Those who view themselves as self-starters or consummately independent persons, for example, benchmark their impairments and ability to function more rigorously than others.

Asked to describe how his day goes, one 74-year-old survivor reports to be “coping” the best he can under the circumstances. He is accustomed to doing all the daily outdoor tasks around his large rural homestead, but now this is too difficult for him. All he can do is “cope” with it, as he says, which in the context of the interview as a whole means to bide his time and meanwhile accept the fact that he is nowhere near to what he used to be. Not viewing himself as a lazy man benchmarks his inability to do chores as something one does not merely accept, but that one waits out until one’s functioning significantly improves. On two occasions, he refers to his sense that time will bring about functioning commensurate with the kind of person he views himself to be.

That’s the way I been coping and because I’ve never been a lazy man, I worked all my life. There’s things I wanna do [that] I just put, let them go. [He later explains:] I say [I’m] all right, but I know I ain’t all right yet, ’cause for I think I know myself better than anybody else except what’s wrong and I think time, I know time, will bring about a change.

Another survivor is more specific about the kind of person he is and how such a person responds to the disabilities of stroke. At 51 years of age, this relatively young stroke survivor, who served in Viet Nam, benchmarks his impairments in relation to the definition of himself as a “fighter,” not a “quitter,” terms

he uses to indicate what someone like himself confronts in no longer being able to work at a job he figures has greater challenges than most. He was a supervisory engineer and iron worker who helped to construct high-rise buildings. He needed to be more physically agile than most to be able to withstand the challenges of not only working at great heights but to do so with skill and dexterity. His love of craft comes through as he picks up a photograph of himself and others standing in front of one of the high-rises he worked on, describing how he put his mark of approval on every detail. Asked whether there is any part of his day now that goes easier than others, his comments show that in contrast to what he once was and how he viewed himself, he now pales in comparison.

No, because I was an iron worker for 27 years. Then I was a line supervisor engineer, as an engineering tech. And, uh, so my life is shot. [To his partner:] Honey, give me that picture on top. This building [showing the picture], 40 story, 43 story Bellow Bank Building in Beach City. That's me, and that's my son that I can't see [son lives too far away]. But, I'm so smart, uh, three or four, uh, people in Beach were bidding on me, 'cause I'm the only one that had high-rise, high-speed construction [experience] of this nature. If you ever go to Beach City, that building, I signed every piece of inspection, concrete, and shoring. I was in charge of everything that happened. I went 60 feet below Commerce Street to do calculations on the foundation.

As the interview continues and various aspects of his present life are described, especially the challenges of his stroke impairment, everyday functional assessment seems to center more and more on a life that seems to be over. The benchmark of who he was and still views himself as being is set so high that his life now is virtually functionless in comparison. He describes that life as now being "wiped out." Other descriptions present a body that has closed down and is no longer useful. At several points, he states that there's no point in going on, suggesting that he might perhaps take his life. Following human subject protection guidelines, the research team followed up on this respondent's reference to possible suicide and found that he was not at risk. But every time this is mentioned, his self-definition comes back into the discussion to assure the interviewer that the fighter he once was won't allow him to do himself in, even now that his life is virtually over. Asked how he feels about his current situation, he responds,

First off, shutted down, I'm not gonna kill myself. Believe me, I got enough medication. I'm a survivor and, uh, I would never try to take my life. My life's gone, but I still wouldn't take it. I never think of hurtin' myself, killin' myself, or doin' any of that bull, dumb-ass [thing]. Hey, if you kill yourself, believe me, you're not goin' to heaven. You're headed straight to hell faster than you can get there. Yes, sir. I live for Jesus and, uh, no, mm-mm-mm. Only crazy people kill their selves.

As he elaborates on his daily life now and the medications he is on that make him tired and listless, the work that he took so much pride in creeps in to define the philosophy that surrounds his sense of being a fighter and survivor. The supporting phrase he uses throughout the interview is "If you quit, they win."

Whereas, on the one hand, his work and continuing sense of self as a fighter benchmark very low functioning, on the other hand the same self-definition purports to keep him alive under the circumstances. Self-definition is a benchmark that not only puts the impairment of stroke in a life context, but can also keep one going in the process.

Not all survivors express such high regard for their work, or convey such marked self-esteem; nor do they all communicate such a strong sense of survivorship. Some view themselves and life with more equanimity, with their self-definition conveying a greater evenness of mind and temper. Who they once were and what they are now does not set the high standard of comparison it does for others. These survivors assess their functioning without the stark contrasts evident in the preceding extracts. One 70-year-old survivor, for example, relays a sense of self throughout his interview that lowers the bar considerably for the everyday functional assessments that follow. At one point, midway into his interview, he is asked what his greatest concerns are now about his body. He responds,

Well, I don't know. I guess I ain't really worried about nothin' [laughs]. I'm not the worryin' kind. . . . I'm just wearin' out a little a day at a time, I guess. [Laughs] I'm tryin' to keep it goin' as long as I can. . . . No, ah, I don't overdo it is the main thing. I just try to take it easy and do little things, don't do big things.

When compared with those of other survivors, such comments convey greater satisfaction with everyday functioning. In these cases, given how the subjects view themselves, disabilities are taken more in stride, accepted in terms of what life brings, or, simply, in terms of what can happen to anyone in the later stages of the life course.

Few of these survivors explicitly define themselves in terms of gender. Those who do discern everyday functional assessment in relation to what they consider a man should be able to do as opposed to what would be expected of a woman. Their reasoning is that men are naturally more active than women, functioning as go-getters and as the leaders of their families and communities. (It is important to note here that although the process of benchmarking appears to cut across gender lines, this reasoning suggests that what specifically serves as benchmarks for male survivors may differ from what serves for female survivors.) One of these men, a 65-year-old survivor who has difficulty finding his words because of his stroke, feels that not being able to get his words out presents him more negatively than it would a woman. Reflecting on his four daughters' concern for his health, he describes their suspicion that he's not as well as he tries to convey, as well as their attempt to keep up the pretense. In the process, he explains that, being the man of the house, he feels bad that they need to patronize him in this way.

And she'll [a daughter] say, "How you feelin', Dad?" "Well, I'm doin' all right," knowing I'm feeling bad, but she don't say anything. And I have, like I said to you I've got four daughters and when we all, they all get together, you know, they [whispering] "Pss, pss, pss, pss, look at Daddy, pss, pss, pss, pss." You know daughters [laughs]. I can sense it, 'cause it was before that "Well, Daddy, you know that ain't right," and now she say "Okay,

Dad.” [Interviewer: You think they patronize you?] Yes, ma’am. And for a man, it’s a bad feeling, yeah.

Another survivor, a 74-year-old man, further specifies his identity as a man by describing his household’s division of labor. His wife is strictly in charge of the inside and he is responsible for the outside, a very significant distinction to him. She always does the shopping and he tends to what he views as a man is obliged to do. Defining himself in these terms means that, because he no longer can attend to the “man-of-the-household’s” responsibilities, he is no longer functional. Asked if he nonetheless might be able to help around the house, he responds that that is what a wife does, not a man, effectively closing off considering that benchmark of everyday functioning. If this survivor can’t do “a man’s job,” in his opinion he is no longer physically functional, even though he might still be able to do the equivalent of what he figures to be woman’s work and perhaps judge himself to be remarkably fit if he did.

COMORBIDITY AND AGE AS BENCHMARKS

Everyday functional assessment also is benchmarked by the condition of survivors’ bodies and their ages. Many stroke survivors experience comorbidities; they do not come in a disease-specific box. For example, a 47-year-old survivor with right-sided numbness, who has difficulty walking due to his stroke, also is experiencing the effects of diabetes. Another survivor has extensive right-sided weakness from a stroke and is on kidney dialysis. A third uses a wheelchair, from the combined effects of a recent stroke, visual impairment from cataracts, and Parkinson’s disease. The benchmarking result of comorbid experiences is that stroke survivors assess their continued functioning in relation to the other conditions that are also affecting them.

The preceding 47-year-old survivor, for example, who has right-sided numbness and difficulty walking, could not respond to any of the interview questions about his stroke without taking account of what else was affecting his mobility. Whether it was questions about a typical day, what life was like before and after his stroke, or his view of the future now that he’d had a stroke, all of his health problems were taken into account as benchmarks of physical functioning. This survivor also had rather extensive knowledge of the course of stroke recovery and recognized that, no matter what one did or the therapy one received, in time there was going to be a certain amount of spontaneous recovery following the initial assault. This benchmarked the functional effects of his stroke differently than it did for those who took only their strokes into consideration or who had little knowledge of the sequelae of stroke.

Asked to think about what his future looks like now, this survivor immediately refers to comorbidities: “Ah [laughs], I see there are a lot of things besides the stroke that I have to deal with.” Encouraged to elaborate, he explains,

When it comes to my, a future for me. Ah, because I’m a diabetic, I’m goin’ blind. The doctor said I got two, two, two months to two years, I could go blind. And I’m tryin’, I’m tryin’ to work through that, but it’s gonna happen. Ah, so, so as it stands, I’m tryin’ to see and I’m concentratin’ on getting my life straight until, until that time comes. But my diabetic, ah, my stroke is gonna heal itself. It’s, it’s up to me to heal my other things.

The interviewer inquires further, “So do you think your stroke has, the stroke itself has changed how you think about your future?” The response makes it clear that the functional assessment of his future is not benchmarked by effects of the stroke alone, but especially by the perceived impact on his functioning of his looming blindness.

No, no. The stroke hasn’t changed a bit the way I think about the future, because as long as I can see, I can, I could do somethin’. But once I go blind, that’s a different story, that’s a different avenue.

In some sense, this survivor is telling us that if one were to complete a formal functional assessment of the effects of his stroke right now and predict the future, what the assessment would foretell would not square with his own appraisal of future functioning. Whereas the results of a formal functional assessment might prompt one to feel positive about the future and be some cause for celebration, an everyday assessment that is benchmarked in this survivor’s terms produces negative outcomes. Here again, the significance of everyday functional assessment is evident—benchmarking shifts about the varied illness contexts of everyday life, making for outcomes that are more complex than disease-specific assessments.

Some survivors have had previous strokes. This presents a different benchmark for everyday functional assessment than that for survivors experiencing a stroke for the first time. Those who have only had their existing stroke have no personal basis for comparing their functioning now with what it might be from the effects of a previous stroke. Certainly, they can compare what life was like before and now after their existing stroke, but they have no basis of comparison from a past stroke experience of their own that ran its course for putting that difference in context. Of course, first-time stroke survivors do compare themselves with other stroke survivors they know and some especially with family members who have experienced strokes. These interpersonal comparisons benchmark the functional effects of stroke for them in a way it does not for those who have no knowledge of the consequences of stroke other than their own, something to which Roth (1963) significantly alerted us.

Survivors who responded to interview questions with little or no basis of comparison other than what their lives were like before and after their strokes tended to assess the functional effects of their strokes in the most striking terms. Such survivors were more likely to state that, as a result of the strokes, their lives were over or, as one of these survivors put it, “my whole life is wiped out.” Before-and-after experience for these survivors was an experience in functional polarity. Benchmarking against a pain-free life with relatively full functional capacity, a stroke survivor who now required the assistance of a walker, used a wheelchair, or who was experiencing concomitant pain in impaired limbs could be a study in despair, if not fear and loathing.

In contrast, the everyday functional assessments of those who have had a history of strokes or who, as one survivor put it, “been around strokes all my life,” are less poignant. Asked if “people’s backgrounds” affect the way they react to strokes, one 67-year-old African American survivor instructs that this even may be evident in others’ reactions to the impairments of stroke survivors.

A lot of times, now, on that, yes, 'cause it's how they grew up. If you grew up around people that's had a stroke, I don't care if you're black, white, green, or what, you should be the same. You know, but if you have never been around anybody that's had a stroke and all of a sudden you're put in there with somebody that's had one, why, yeah, you kinda react a little different. [Interviewer: In what ways, do you think?] Well, you take somebody that's never been around and they'll ask things, and that bothers you.

As the next extract suggests, those who "grew up around people" with stroke, or who otherwise have personal experience with stroke recovery, are less likely to view survivors as "oddly" dysfunctional. Following up on the respondent's last comment "and that bothers you," the interviewer probes further and the respondent explains:

Well, that bothers them that, you know, that they would see me staggerin'. I can't lift with my left hand. It's just, it's odd, you know, that they think he's odd. Anybody that different than they are, they're odd. And if they've never been around one, some of them is just dumb enough to ask all kind of questions.

Even those who have not had strokes can differ in their reactions to the effects of stroke. One could surmise that those who have not had strokes, but who "grew up around people" with stroke, would not be as strident in their reactions to stroke survivors as those for whom the effects of stroke were unrecognizable. What is being pointed to is the possible stigmatizing effects of responding to stroke in the absence of experience with, or knowledge of, stroke. The direct consequence of having no benchmarks for reacting to the absence of function in others can be to view it as odd. This survivor perceives this as "dumb," if not explicitly stigmatizing.

Age also figures into everyday functional assessment. Age does not signal specific comorbidities, but it does work to inform older stroke survivors that "at their age," so to speak, a variety of age-related somatic conditions can normally benchmark reduced functioning. The younger stroke survivors tend to benchmark functional assessment more in terms of self-definitions, in relation to what life was like before and after their strokes. The older survivors, in contrast, tend not to look back as starkly on their lives. They are more likely to figure that, at their age, any number of other bodily conditions besides stroke can compromise physical functioning. If older survivors are concerned with the impact of their strokes on their capacities to carry on, they typically are more stoic than are younger survivors about what this implies in the broader scheme of their lives. If the expressly physical effects of a stroke can be similar for a younger and an older survivor, everyday functional assessment is likely to be evaluated more negatively by the young.

The vocabulary of age was not commonly used by the younger survivors, those in their forties and fifties. In contrast, older survivors, especially those in their seventies and eighties, frequently responded to questions about the functional effects of their strokes with explicit reference to age. One 80-year-old survivor put it this way when asked if he feels any different about himself since his stroke:

No. Same thing. [Interviewer probes for feelings of depression.] No, I don't get depressed. No, it don't bother me. It's just, but, and like I said it's the breaks of life. When you get old, you're gonna get, you're gonna have them things. There's a couple of brothers in Texas who've already had two strokes.

Referring to the "breaks of life," this survivor suggests that stroke is something to be expected as one gets older, along with all the other problems that come with getting on in years. In the context of age and associated somatic ravages, the functional effects of a stroke seem to decrease in significance.

TASKS OF DAILY LIFE AS BENCHMARKS

Regardless of self-definitions, comorbidities, and ages, all survivors are challenged by the tasks of daily life. Tasks such as getting up in the morning, making coffee, taking a breath of fresh air outdoors, tending to the usual chores around the house, going out in public, and even passing time pose challenges to those with reduced functioning. Each of these tasks and countless others benchmark in new ways the everyday functional assessments of stroke survivors. Some survivors, of course, are supported in dealing with daily tasks by concerned and available caregivers; others manage more on their own, even when there are caregivers in proximity. Some survivors use assistive devices such as wheelchairs, walkers, and quadcanes; others awkwardly amble about without them. These work together in various ways to differentially construct the everyday meaning of functional capacity.

Everyday functional assessment in this area can be amazingly ordinary, being marked by the most mundane activities of daily living. Still, as ordinary and mundane as these are, they can be significant benchmarks of functional capacity. The minutiae of daily living loom in importance as survivors periodically check themselves out, so to speak, in reckoning functional capacity. An important thing to note in this regard is that this area of everyday functional assessment continuously shifts about in its results as various mundane benchmarks present themselves daily for survivors' considerations.

One 67-year-old stroke survivor, for example, who lives in a sandy rural area, spent a great deal of time before his stroke visiting with neighbors and friends and tending his property. He describes his active prestroke routine in detail:

Oh, I gotta walk. Hell, I've, up till in October before this happened [his stroke], I was walking four and five, six, seven miles a day. All in that sand. I'd have every kid in the country around here followin' me. We'd go out there and walk, us kids, and I'm . . . you asked if we drive in down here, "Where's Grandpa at?" They'll tell ya. They'd show you exactly where I was at and what I was doin', these kids would. [Asked about how that's changed.] Now, I've walked right out the door out on the front porch and I give out. [Asked how he feels about that.] Oh, it's bad, it's bad. I have some wonderings when we go downtown or go somewhere everyday, 'cause I'm used to workin' all my life.

This survivor had considerable pride of property and took pleasure in helping his neighbors, which further benchmarked his sense of being able bodied. As ordinary a matter as getting

onto his tractor and “mowin’ and gradin’” signified functional capacity, which, following his stroke, completely plummeted:

Oh, I’d get up, get on my little tractor and go out here and get to mowin’ or gradin’ or work of some kind or other all day long. Helpin’ a neighbor. [Asked how different this is now.] Yeah. I haven’t even started a lawn mower this year. I’ve got three of ‘em sittin’ out there. I’ve got a tractor and a bush hog [heavy duty brush remover]. Haven’t even put the bush hog on the tractor. Give you an idea how I can’t do it, what ain’t plannin’ on it. Just can’t work. Like I’d like to. I was out goin’ all the time like that.

Survivors do not all passively orient to these functional benchmarks of daily living. Some actively “test” their abilities to deal with tasks they were formerly able to complete. It’s evident that daily tasks such as “mowin’ and gradin’” do not simply challenge these survivors as static features of their environments, leading them to calculate functional capacity in simple response to them. Rather, they seek out bases for evaluating their functional capacities as they go about their daily lives, to see whether they still measure up to their challenges. In this regard, the tasks of daily life are less static benchmarks for everyday functional assessment as they are engaged by survivors in explicit attempts to figure what it means in concrete terms to be functionally able or incapacitated.

The preceding stroke survivor’s comments on daily life are telling in this respect. At several points in his interview, he refers to a wooden ramp that he and his grandsons are building in front of his mobile home. The ramp will make it easier to go in and out of the house because he has difficulty negotiating the stairs with his walker. This survivor is clearly challenged by the construction process, not just as the passive participant in a project that presents a benchmark for functional capacity, but as an active seeker of just what he can and can no longer do effectively under the circumstances. Commenting on the part he tries to play in the project, he explains,

I can’t do things like I want to do ‘em. I gets a little bit shook up, you know? I can’t grab that 2×6 and walk out like I could before. That, that kinda, I mean I almost want to grab that 2×6 , you know, still want to do it, and I can’t do things like that. Kinda, kinda bothers me. [Asked how this bothers him.] Well, I just, uh, I can’t do like I want to do. [I gets angry] at myself. At myself I am. I mean I want to reach out and grab it and do somethin’ with it and I can’t, you know. I’ll fall and bust my [laughs] yeah.

Later in the interview, he returns to the functional challenges of the ramp project, again describes how he actively tests himself, and once more designates how this makes him feel:

I try to get out and do a little more. Just find different things that you can’t do that you [see it’s not the same]. I mean when you were here before, you know, but I was just findin’ how they are now for me. Like I try to stand up on a bunch of boards. Yeah, you find somethin’ new every day that you can’t do, like especially when you get out here trying to do stuff.

At the behest of the interviewer, he then relates this to good days and bad days, picking up on the everyday functional capacity associated with grabbing a 2×6 . In the process, he

not only benchmarks a specific incapacity, but conveys what the practical meaning of a bad day is in this situation:

I’m just awkward. I’m liable to be walkin’ along, all of a sudden I’ll be just fallin’ to the left or right, most of the time to the left, just awkward. Lose my balance. [Asked to relate this to good days and bad days.] I usually goof up. On a good day, I’ll go out and somethin’. Until I do somethin’ wrong, then it messes me up and I have to start all over again the next day, you know. In other words, I’ll goof up and I guess not feel too good [about it] and man I can’t do that. I can’t and I prove it, that I can’t do it. Like I say, I’ll pick up that 2×6 and, hey, you know you ain’t supposed to do that. You throw it down and, like I say, I goofed. I’ll get one end of it and pull it instead of carrying the thing like I normally would.

Active benchmarking shows the complications of everyday functional assessment. In seeking the daily benchmarks they do, survivors actually construct diverse senses of their impairments, constructing good and bad days, or good and bad moments, as they go along. In repeatedly challenging themselves by actively benchmarking daily tasks to assess their functioning, some survivors can actually effect bad days for themselves or, alternatively, produce good days.

Not all are as active as the preceding survivor was in their daily benchmarking. Some simply attend to whatever daily life brings with it, figuring their everyday functional capacities in the process. Others are considerably dismayed by their inabilities and actually try to hide from others what they no longer can do, rather than venturing forward to see how effective they can be. One survivor, for example, who unexpectedly found that he could no longer make good on the habit he’d developed of helping his granddaughter with her homework, was bothered so much by this that he tried to cover up for the failing.

You know, my granddaughter, she’d go out to school. She’d come in the, ah, about three o’clock she come home. I used to jump in there and help with her homework but, unfortunately, I can’t do it anymore. And that weighs hard on me, too, sometimes, you know. She’ll say, “Granddaddy, read this to me.” or “Granddaddy, help me.” [Laughs.] And I try to make up some lie. I shouldn’t say that I lie, but I’m, excuse to get words in there.

Not all benchmarking relates to habits and responsibilities that were regular parts of daily life before a stroke. There are challenges that serendipitously crop up for the first time following a stroke to become benchmarks of physical functioning.

Some serendipitous benchmarking occurs around the home. For example, when young grandchildren visit and bounce up and down on a stroke surviving grandfather’s knees now, following his stroke, he wonders if the “soreness” and the difficulty walking he feels is the result of the bouncing or the stroke.

When my grandchildren come over and, I think that’s the cause of my soreness, you know how kids jump on you? And, but there are two of ‘em, so baby hop on papa. I think that’s what upset me that first time. Now that soreness is leavin’, but I ain’t had no visitation with them for a while. I don’t know whether they caused it or it’s my sickness, but I been takin’ it easy.

Interestingly enough, this extends to the assumed courtesies of being interviewed about the recovery experience, a rather unusual event in the lives of these survivors. Asked what he now feels frustrated by, one survivor comments, "Yes, ma'am. And you know, even when we're conversating with you, when I can't get my words out, or when I'm trying to convey to you, it's frustrating."

Serendipitous benchmarking seems more commonplace in public settings. Survivors talk at length about how they manage to get about outside their homes, especially in public. They learn serendipitously, for example, that they no longer can accompany their wives on shopping trips or that the independence in public they once took for granted now requires others' support. One survivor describes the surreptitious way his wife makes it possible for him to appear normal outside their home. In the following exchange, interviewer and survivor discuss the survivor's wife's inconspicuous support while they attended his grandson's concert and when they go shopping, enabling the survivor to be in public without appearing to be disabled.

- Survivor: Disabled. You know, you can't do things the other people do. [By the] time I go get a cup of coffee, it's cold by the time I get back because . . . you know, it takes longer. That's the reason why I got her [his wife]. She does all that stuff.
- Interviewer: When you said, one example you gave earlier was that yesterday at the concert, you were sliding and she sat by you.
- Survivor: Yeah, she's sittin' on my left and she slid her chair right up against mine, put her shoulder there where I can lean against her, keep me from slidin' out, fallin' out of this chair.
- Interviewer: Are there, uh, any other times?
- Survivor: Oh, yeah. Lot of times like that, she does different things like that. She sees it ahead of time and a lot of time, we start in the store, she'll sneak up beside of me, just accidentally, you know.
- Interviewer: Um-hmm.
- Survivor: Be aside of you. She ain't trying to tell you nothin', but I could see it. [Laughs.]
- Interviewer: And she does that for what reason?
- Survivor: To keep me from fallin' and bustin' my back end. [Laughs.]

Serendipitous benchmarking also comes in imaginary form. Several survivors stated that the tasks of daily life caused them to imagine what life might have been like if things had been worse. Some commented, for example, that they could have had a "full-blown" or more damaging stroke, which would have left them even more incapacitated. Such negatively imagined benchmarks made things appear to be better than they might have been. Some survivors stated that they were not yet ready to die, adding that they would keep going till then, benchmarking their current functioning in relation to continued living. Others commented that they weren't yet ready for a nursing home, benchmarking themselves against the implied dysfunction of nursing home residents. One simply pointed out, "I'm alive. Everyday is a blessing, especially when I got my two feet and I'm happy to be alive."

The imagined future also was a serendipitous benchmark. Survivors looked ahead, many for the first time in their situations, to what they now hoped to become, most of which was portrayed positively. As one survivor explained, referring to what new medications might provide, he looked forward to the possibility of being human again, an imagined benchmark that he explained elsewhere in the interview helped to keep him going and not wanting to do away with himself.

See, maybe in five years, they'll have a medication out that would work on me and I can go out of here and be human. I'm waitin' for that break in life. They come up with new formulas and medications everyday. They tell you on that television right there.

CONCLUSIONS

The stroke recovery experience is steeped in everyday functional assessment. From self-definitions, to comorbidity status and age, and to the tasks of daily living, survivors reckon their disabilities against a variety of benchmarks. This extends well beyond what formal functional assessment indicates, onto the continuously emerging terrain of daily living.

What lessons does everyday functional assessment provide for understanding the experience of stroke recovery? One lesson is that the standards or benchmarks that survivors take into account in assessing their physical capabilities produce highly varied outcomes. Assessments relate to survivors' lived experiences, the baselines of which are not limited to the standards set in formal assessment. Benchmarks fluctuate because they are tied to working identities, a broad range of somatic conditions, and the tasks of daily living. Researchers and professionals would do well to consider benchmarking as well as formal functional assessment in their work, because, taken together, they provide a more complete understanding of what it means to be functional in relation to the full round of daily experience for survivors.

A second lesson is that, without an eye toward everyday life, formal functional assessment would lead us to believe that "all that matters" in assessment is what the formal assessment enterprise deems significant. This would suggest that such formal assessment concerns as the range of motion of limbs, and the ability to put various ranges of motion into effect in designated tasks, are the primary considerations. In contrast, the interview material shows that a spectrum of other considerations figure into survivors' functional assessments, some of which are even serendipitous and imagined. The lesson here is that survivors are far from being exclusively attuned to the parameters of formal assessment; in actuality they are as much or more concerned with the functional consequences of self-definitions, comorbidities, age, and the tasks of daily living. In the context of everyday life, the yardsticks of formal functional assessment recede in significance as matters of more immediate practical concern loom in importance. Survivors are not just patients, but take on many other roles in figuring their capabilities, which themselves fluctuate as they go about their everyday lives.

A third lesson relates to the behavioral outcomes of everyday functional assessment. Although survivors may learn the results of formal functional assessments, there is no guarantee that they will keep them in mind after they leave the formal assessment

setting. What the interviews do indicate is that survivors are attuned to functional benchmarking, actively engaging in the assessment of related skills on a daily basis. It is matters that are kept in mind and that are of daily interest that have meaningful behavioral outcomes, not matters unknown or forgotten. The lesson here is that we stand the best chance of understanding the way stroke survivors behave after discharge to their home environments if we also take account of the kind of information and yardsticks they actually use in assessing their functional capacities.

This article has focused on the process of benchmarking for stroke survivors and has identified three areas of experience used to mark everyday functioning. The aim was to revisit an idea put forth years ago by Roth and to examine its application to a population whose illness experience is relatively unexplored. What remains to be done is to extend this to various subpopulations of stroke survivors—to women as well as to men, for example—to see if the particular areas of benchmarking and kinds of benchmark identified here or others vary with them. We have only begun to explore this in this article, as it may relate to age, work experience, and a few other background characteristics. We've only intimated, for example, that because of traditional differences in the household division of labor for the generation studied, men may benchmark their everyday functioning in different terms than women. This has to be systematically examined, which, because of the sampling restrictions of the VA study, could not be done here. However, we do plan to compare the ethnic groups for their respective areas of benchmarking and kinds of benchmark, and we recommend to others that additional background characteristics, such as age and class, be systematically examined as well. Taken together, such studies would provide a fuller picture of what it means to survive a stroke.

ACKNOWLEDGMENTS

This research was supported by Grant Award NRI 98-183-1 from the U. S. Department of Veterans Affairs Office of Research and Development to Maude R. Rittman, PhD, RN, who was the principal investigator.

Address correspondence to: Jaber F. Gubrium, Department of Sociology, 312 Middlebush Hall, University of Missouri, Columbia, MO 65211-6100. E-mail: gubrium@missouri.edu

REFERENCES

- Australian Institute of Health & Welfare. (1999). *Heart, stroke and vascular diseases, Australian facts*. Canberra, Australia: Australian Institute of Health & Welfare and the Heart Foundation of Australia.
- Albrecht, G. L., Fitzpatrick, R., & Scrimshaw, S. C. (Eds.). (2000). *The handbook of social studies in health & medicine*. Thousand Oaks, CA: Sage.
- Becker, G. (1993). Continuity after a stroke: Implications of life-course disruptions in old age. *The Gerontologist*, 33, 148–158.
- Becker, G. (1997). *Disrupted lives: How people create meaning in a chaotic world*. Berkeley: University of California Press.
- Becker, G., & Kaufman, S. R. (1986). *Socio-cultural mechanisms of rehabilitation in old age*. (Final Report; Grant #AG04053). Washington, DC: National Institute on Aging.
- Becker, G., & Kaufman, S. R. (1988). Old age, rehabilitation, and research: A review of the issues. *The Gerontologist*, 28, 459–468.
- Becker, G., & Kaufman, S. R. (1995). Managing an uncertain illness trajectory in old age: Patients' and physicians' views of stroke. *Medical Anthropology Quarterly*, 9, 165–187.
- Blaxter, M. (1976). *The meaning of disability*. London: Heinemann.
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness*, 4, 167–192.
- Bury, M. (1996). Defining and researching disability: Challenges and responses. In C. Barnes & G. Mercer. (Eds.), *Exploring the divide: Illness and disability*, (pp. 17–27). Leeds, UK: The Disability Press.
- Carr, J. H., & Shepherd, R. B. (1982). *A motor learning programme for stroke*. London: Heinemann.
- Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. New Brunswick, NJ: Rutgers University Press.
- Davis, P., Bamford, J., & Warlow, C. (1989). Remedial therapy and functional recovery in a total population. *International Disability Studies*, 11, 40–44.
- Doolittle, N. D. (1990). *Life after stroke: Survivors' bodily and practical knowledge of coping during recovery*. Unpublished doctoral dissertation, University of California, San Francisco.
- Doolittle, N. D. (1992). The experience of recovery following lacunar stroke. *Rehabilitation Nursing*, 17, 122–125.
- Doolittle, N. D. (1994). A clinical ethnography of stroke recovery. In P. Benner (Ed.), *Interpretive phenomenology: Embodiment, caring and ethics in health and illness*, (pp. 211–223). Thousand Oaks, CA: Sage.
- Douglas, J. D. (Ed.). (1970). *Understanding everyday life*. Chicago: Aldine.
- Fujiura, G. T., & Rutkowski-Kmitta, V. (2001). Counting disability. In G. L. Albrecht, K. D. Seelman, & M. Bury (Eds.), *Handbook of disability studies* (pp. 69–96). Thousand Oaks, CA: Sage.
- Glaser, B. G., & Strauss, A. L. (1968). *Time for dying*. Chicago: Aldine.
- Greenhalgh, S. (2002). *Under the medical gaze: Facts and fictions of chronic pain*. Berkeley: University of California Press.
- Holstein, J. A., & Gubrium, J. F. (Eds.). (2003). *Inner lives and social worlds*. New York: Oxford University Press.
- Kaufman, S. R. (1988a). Stroke rehabilitation and the negotiation of identity. In S. Reinharz & G. Rowles. (Eds.), *Qualitative gerontology*, (pp. 82–103). New York: Springer.
- Kaufman, S. R. (1988b). Illness, biography, and the interpretation of self following a stroke. *Journal of Aging Studies*, 2, 217–227.
- Kaufman, S. R. (1988c). Toward a phenomenology of boundaries in medicine: Chronic illness experience in the case of stroke. *Medical Anthropology Quarterly*, 2, 338–354.
- Kaufman, S. R., & Becker, G. (1986). Stroke: Health care on the periphery. *Social Science and Medicine*, 22, 983–989.
- Roth, J. A. (1963). *Timetables*. Indianapolis: Bobbs-Merrill.
- Stineman, M. G., Maislin, G., Fiedler, R. C., & Granger, C. V. (1997). A prediction model for functional recovery in stroke. *Stroke*, 28, 550–556.
- Taub, E., Uswatte, G., & Pidikiti, R. (1999). Constraint-induced movement therapy. A new family of techniques with broad application to physical rehabilitation—a clinical review. *Journal of Rehabilitation and Development*, 36, 237–251.
- U.S. Department of Health & Human Resources. (1996). *Post-stroke rehabilitation: Clinical practice guidelines*. Gaithersburg, MD: Aspen Publishers.
- Üstün, T. B., Chatterji, S., Bickenbach, J. E., Trotter, R. T. II, & Saxena, S. (2001). Disability and cultural variation: The ICIDH-2 cross-cultural applicability research study. In T. B. Üstün, S. Chatterji, J. Bickenbach, R. T. Trotter II, R. Room, J. Rehm, & S. Saxena. (Eds.), *Disability and culture: Universalism and diversity*, (pp. 3–19). Seattle: Hogrefe & Huber.
- Wade, D. T., & Langton, R. (1987). Functional abilities after stroke: Measurement, natural history and prognosis. *Journal of Neurology, Neurosurgery, and Psychiatry*, 50, 177–182.
- Weigert, A. J. (1981). *Sociology of everyday life*. New York: Longman.
- Williams, G. (2001). Theorizing disability. In G. L. Albrecht, K. D. Seelman, & M. Bury (Eds.), *Handbook of disability studies* (pp. 123–144). Thousand Oaks, CA: Sage.

Received May 2, 2002

Accepted November 11, 2002

Decision Editor: Charles F. Longino, Jr., PhD