MEDICAL KNOWLEDGE AND FUNCTIONAL ASSESSMENT 
IN THE EVERYDAY LIVES OF STROKE SURVIVORS 

By 

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Abstract of Dissertation Presented to the Graduate School of the University of Florida in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy

MEDICAL KNOWLEDGE AND FUNCTIONAL ASSESSMENT IN THE EVERYDAY LIVES OF STROKE SURVIVORS

By

Craig Boylstein

December 2002

Chair: Jaber F. Gubrium
Department: Sociology

Medical knowledge and functional assessment are analyzed with scaled measurement instruments and qualitative data from interview narratives. Focusing on functional ability after an acute stroke event, this dissertation presents an account of functional independence in self-care and routine activities by presenting scaled item results and narrative themes. These findings suggest that clinical measurement scales are adequate in assessing the body as a biological phenomenon, but fail at capturing one’s sense of embodiment, of the subjective experience of being an embodied entity. With quantitative and qualitative assessments of biological and sociological factors, we can better understand functional recovery after a traumatic health experience such as stroke.
CHAPTER 1
METHODOLOGICAL ISSUES OF FUNCTIONAL ASSESSMENT

Aaron Cicourel (1964 pp.1-2) said “sociological research and measurement require something like a ‘theory of instrumentation’ and a theory of data so that we can disentangle the observer’s presence and procedures from the material he labels data.” My study takes this as its point of departure. My research focus is the assessment of functional activity, specifically investigating how functional ability is assessed for those rehabilitating after stroke. The central research question this dissertation answers is “what is the relationship between item-rated assessments of functional status and day-to-day functioning?”

Stroke is one of the most common diagnoses requiring medical rehabilitation (Stineman and Granger 1998). The high prevalence and high economic costs of stroke-related disabilities make the evaluation of stroke patient services a major concern for health care practitioners (Duncan and Lai 1997). Stineman et al. (1995) said that in developing a functional perspective regarding disability and physical rehabilitation, researchers must assess functional limitations and measure social-context indicators of disability. The goal of rehabilitation is to restore the functional capacities of those with disabilities or chronic diseases so they can function successfully after returning to the home environment.

Granger (1984) outlined a functional perspective that focuses on the care of impaired people, on maximizing their quality of life, and on helping to maintain their independence in important daily activities. If this is indeed the goal of medical
rehabilitation, then it would seem necessary to assess whether the types of functioning being measured by clinicians indeed match the functional activities stroke survivors are concerned with in their daily living. Concepts such as attitude, motivation, and social support are important indicators in assessing one’s level of disability (Granger 1984).

Granger and Gresham (1984 p. 8) stated that:

For too long, we have taught blind people to fold sheets and retarded persons to put nuts and bolts into boxes, regardless of their particular characteristics and environments. . . . Public policies and programs whose purposes are to help chronically ill and disabled persons will not be more effective until we have more sophisticated measures of human function on which to base these programs.

This research project examines how sophisticated measures of human functionality compare to human functioning in everyday life.

**Functional Independence and Frenchay Activities Index Measures**

Numerous functional measurement tools are available scientific investigators and health care professionals. My focus is primarily on the Functional Independence Measure (FIM). The FIM is used by a multitude of medical practitioners in a wide variety of circumstances, particularly in acute rehabilitation settings. It is the most widely applied instrument in determining patients’ rehabilitative status (Williams et al. 1997). The FIM is the tool and measurement system of the Uniform Data System for Medical Rehabilitation (UDS), the goal of which is to nationally document rehabilitation outcome results as objectively as possible (VAMC 1990). Approximately 60% of U.S. rehabilitation hospitals participate in the UDS (Hinkle 2000). The FIM is to serve as a uniform language and measurement system for rehabilitation (VAMC 1990). It is designed to assess the functional status of the physically impaired, and the effectiveness of a given rehabilitative treatment. As Granger et al. (1993) noted, the FIM helps health practitioners determine the amount of services a person requires, and the effectiveness of
the rehabilitative treatment a person receives. The UDS collects FIM results from over 400 facilities nationwide (Williams et al. 1997).

**Components of Functional Independence Measure (FIM)**

The FIM consists of 18 items whose scores range from 18 to 126. These items are divided into motor and cognitive subcategories. The first 13 items make up the motor subtotal score, with possible scores ranging from 13 to 91. These motor items are eating; grooming; bathing; dressing upper body; dressing lower body; toileting; bladder management; bowel management; bed, chair and/or wheelchair transfer; toilet transfer; tub or shower transfer; walking or wheelchair locomotion; and stairs locomotion.

- A score of 1 for a given item means total assistance is needed for that activity: subject can complete 0-24% of the activity
- A score of 2 on a FIM item means maximal assistance is needed: subject can complete 25-49% of the activity
- Scores of 1 and 2 are seen as complete dependence.
- A score of 3 means moderate assistance is needed: subject can complete 50-74% of the activity
- A score of 4 means minimal assistance is needed: subject can complete 75-90% of the activity
- A score of 5 means the subject requires supervision and less than 10% assistance while performing the activity.
- A score of 3, 4, or 5 on a given item is seen as modified dependence.
- Scores of 6 and 7 indicate that the subject does not require a helper
- 6 = modified independence, where subject uses a device or takes medication in order to perform the activity
- 7 = complete independence, where the subject can complete the activity in a safe and timely manner without help, use of a device, or supervision

The remaining 5 items of the FIM make up the cognitive subtotal score. These are comprehension, expression (communication subset), social interaction, problem solving,
and memory (social cognition subset). Again, item scores range from 1 to 7 (minimum cognitive subtotal score of 5, maximum cognitive subtotal score of 35) with similar scoring rationale as with the motor scoring. Granger et al. (1993) found that tub and shower transfer, grooming, locomotion, and dressing lower body, are more predictive than other FIM items of requiring help (measured in minutes; accounting for 95% of the variance). Dressing lower body and social cognition subset items are reported as stronger predictors than other FIM items of general life satisfaction.

**Assessment of FIM**

In doing a meta-analysis of over 40 reports that used the FIM in the post-stroke population, Hinkle (2000) found inconsistent reporting in patient demographics and characteristics, as well as in the time participants are assessed. Some measured post-stroke patients at admission and other researchers performed the FIM assessment at discharge. Some studies occur in Sweden and Japan, with different FIM ranges possibly resulting from cultural variation in instrument scoring. Hinkle concludes that the research to date on post-stroke functional assessment offers incomplete information, not allowing one to say with certainty that the results of the studies can be generalized to the overall stroke population. Hinkle calls for greater uniformity in measurement so that cross-comparisons of studies become possible, thus providing more use-value for clinicians and researchers.

Yet even if FIM measurement is conducted across studies with uniform demographic data and uniform timeframes post-stroke (discharge, 1 month, 6 months, 12 months), the question arises “what insight does this medical knowledge provide researchers and medical practitioners regarding functional status of stroke survivors in home and public settings?” This question follows the primary research question stated
earlier regarding the relationship between item-rated assessments of functional status and day-to-day functioning. More specifically, item-rated assessments are the primary measurement tools researchers and medical practitioners use in assessing the functional status of stroke survivors. Those survivors who are assessed as high functioning are believed, at least for all practical purposes, to be able to successfully function at home and in public. Ninety-seven percent of stroke patients with a FIM score of 110 or greater are discharged to the community (Granger et al. 1992). This large percentage of high-functioning stroke survivors who are discharged to the community provides support for the assumption that item-rated assessment scores are used as medical insight into functional ability across a variety of settings. In essence, functional ability as it pertains to medical knowledge is seen as a universal concept. What this statement implies is that a general functional assessment such as the FIM, which is generally rated at the hospital site, is used to assess the everyday functioning of the patient, with the assessment score indicating future functional success at home and in the public after a stroke.

Granger et al. (1993) concluded that a functional assessment measure such as the FIM should be compared with care burden and subjective life satisfaction measures in order to reflect the impact of a disability on one’s life and on community resources. Stineman and Granger (1998) encouraged a commitment to long-term follow-up of patients who returned to the community in order to better monitor and compare outcomes for patients who received various types and levels of rehabilitative services. What is ignored in these conclusions is that a life-satisfaction questionnaire creates a conceptual scheme a priori to even a peripheral understanding of the survivor’s life as expressed by the survivor. That is, the investigator constructs items, with the items treated as equally
relevant to all participants. Furthermore, such scaling devices limit the answer possibilities of the respondent, ultimately resulting in an analysis of the respondents that is constructed mostly outside of the respondents’ everyday lived experience.

For example, as I went out into the field, going to the homes of stroke survivors, one of the measurement scales implemented for each participant was the Geriatric Depression Scale (GDS). The GDS consists of 30 items to be answered either “yes” or “no.” As I went through the GDS with survivors and, separately, with their caregivers, I frequently received answers such as “maybe,” “well I like being at home but I also like going out and doing new things,” “I don’t know how to answer that,” “not usually,” “that’s a biased question,” and “well sometimes yes and sometimes no.” I would then say, “well, if you had to answer yes or no, what would you say?” The point is, oftentimes the everyday life of a stroke survivor cannot be accurately reflected through a series of yes or no statements, and sometimes, even yes or no answers must be negotiated. Everyday life requires constant work, with meaningful activities produced by the interrelationships of the stroke survivor and those people and things existing in his lived environment that are taken into account by him. However, if common assessment scales are the scientific measurement devices used in long-term follow-up, the meanings to the everyday lives of stroke survivors result from how the researchers have taken the world into account, which may or may not be how the respondents themselves attach meaning to specific daily events. That is, what is seen as meaningful to the researcher may be seen as meaningless to the researched and vice versa.

Momentarily setting aside the theoretical/measurement issue discussed in the preceding paragraph, we can follow Stineman and Granger’s (1998) advice for long-term
follow-up, using common assessment techniques. One outcome of extensive follow-up assessments for those who return home may be the discovery of discreet recovery pathways for certain groups of stroke survivors. If clinicians and researchers rely solely on FIM scores in analyzing recovery pathways, it could be possible that five distinct groups at discharge home are distinguished

- Highly dependent: FIM score ranging from 18-36
- Moderately dependent: FIM score ranging from 37-53
- Modified dependent: FIM score ranging from 54-90
- Moderately independent FIM score ranging from 91-107
- Highly independent: FIM score ranging from 108-126

Focusing on the motor subscore of the FIM, Stineman et al. (1995) pinpoint three functional categories

- Low: Motor-FIM 13 to 55
- Moderate: Motor-FIM 56 to 64
- High: Motor-FIM 65 to 91

Controlling for demographic variation such as race, age, gender, and income, FIM score improvement or nonimprovement can be measured at various stages of the recovery process. Those with similar FIM scores, as well as similar functional trajectories, may be concluded to have similar recovery pathways. The model of Stineman et al. (1995) could be used to provide the matrix presented in Table 1-1.

Categorizing motor functioning in such a way can provide a great deal of nationwide data when these categories are created by implementing a universal assessment tool (such as the FIM) and then aggregating the assessment scores of stroke survivors into a database (such as the UDS). Coupled with life satisfaction and burden of care measures, and consistently controlling for demographic variation, such a database would give clinicians and researchers a good understanding of the recovery patterns of
stroke survivors and the effects of certain rehabilitation techniques. This indeed seems to be the goal of the UDS. One question, however, remains. Are stroke survivors who are in the same recovery category really having similar recovery experiences? The relationship between item-rated assessments of functional status and day-to-day functioning is made clearer by using a specialized group of stroke survivors in assessing relationships between measurement devices such as the FIM and FAI and the everyday experiences stroke survivors themselves express. In particular the major category under study will be high functioning stroke survivors (as defined by the categorization model constructed by Stineman et al.) who remain in this category at discharge and one month after discharge.

Table 1-1. Motor-FIM assessment at discharge to community

<table>
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<th>Low</th>
<th>Moderate</th>
<th>High</th>
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<td>Group 2</td>
<td>Group 3</td>
</tr>
<tr>
<td>through time</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No improvement through time</td>
<td>Group 4</td>
<td>Group 5</td>
<td>Group 6</td>
</tr>
<tr>
<td>Decrease in motor functional</td>
<td>Group 7</td>
<td>Group 8</td>
<td>Group 9</td>
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<tr>
<td>assessment score through time</td>
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Duncan et al. (2000) discussed the elusiveness of characterizing stroke recovery. They find precise definitions for recovery lacking, with most studies using measures of impairment assessment, and a few studies defining recovery via the use of a quality of life measurement. Duncan et al. (1992) find many natural history studies of stroke measuring activities of daily living (ADL) rather than specific motor functioning when defining stroke recovery. Note that ADL may be accomplished through the use of the uninvolved limb, compensating for the loss of functioning in the impaired limb. Further, many studies measure stroke survivors in rehabilitative settings, limiting the
generalizability of the results to those survivors who receive such rehabilitation. Many studies also fail to distinguish the heterogeneity of stroke survivor groups (minor, moderate, severe stroke) as well as the time intervals of functional measurement.

Neurological function is believed to improve during 30 days after stroke, with more severe stroke survivors improving up to 3 to 6 months after the event (Duncan and Lai 1997; Duncan et al. 2000). Even the mildest stroke survivors are usually not able to fully recover their prior level of physical functioning. Recovery patterns are found to be dependent upon an interaction of time and stroke severity with the percentage of recovery being dependent upon how recovery itself is defined (Duncan et al. 2000). Larger recovery percentages are found if measured against a disability baseline (57.3%), fewer if measured against a baseline of impairments, with less than 25% found to be recovered if measured against the baseline of prior functioning. Without a clear understanding of what recovery means for stroke survivors, and without clearly delineating homogeneous groups among a heterogeneous population such as stroke survivors, the analysis of outcome results as favorable/unfavorable is premature. In analyzing the effectiveness of various rehabilitative treatments, Duncan (1997) finds motor-function improvement to be limited to stroke patients with rather high functioning at baseline (patients with volitional movement). Further, Duncan finds that for interventions to be effective, they must have the active participation of the patient, who is also willing to continually repeat the exercise (repetitive training/large amount of practice).

Referring back to the quote from Granger and Gresham (1984), measuring functional improvement based on the folding of sheets and the putting of nuts and bolts into boxes may not be useful for those concerned with functional assessment once the
patient is discharged to the community. While the FIM may be useful in measuring one’s ability to independently perform routine, standardized ADL, what can it tell us about the daily problems those categorized as moderately or completely independent routinely face due to their physical limitations post-stroke? One answer to the question I have just posed is that it is at this point in the analysis of the meaning of functional independence that the quality of life measure and functional assessment inventory come into use. While it is beyond the compass of the current report to systematically analyze each measurement scale used in assessing stroke recovery, it would also be methodologically naïve to completely ignore the fact that there are different scales used to measure different aspects of the stroke recovery experience.

**Assessment of Frenchay Activities Index (FAI)**

One measurement of ADL is the Frenchay Activities Index (Holbrook and Skilbeck 1983), which is specifically designed to go beyond measuring the ability for self-care to measuring lifestyle. The Frenchay Activities Index (FAI) is commonly used in assessing more complex activities that the stroke survivor is presumed to deal with in reintegrating into the public and domestic milieus (Wade et al. 1985). The FAI consists of 15 items, which are then scored using a Likert-like scaling format. The possible answers for the first 2 items, preparing main meals and washing the dishes, are 0 = never; 1 = under once weekly; 2 = 1-2 times a week; 3 = most days. The possible answers for items 3-10 (washing clothes, light housework, heavy housework, local shopping, social occasions, walking outside >15 minutes, active pursuit of a hobby, driving/bus travel) are 0 = never; 1 = 1-2 times in 3 months; 2 = 3-12 times in 3 months; 3 = at least weekly. Item 11 deals with planned travel, 12 with gardening, 13 with household/car maintenance, 14 with book
reading, and 15 with paid work. These fifteen items are designed to measure the ability of stroke survivors to survive socially rather than simply survive physically.

The three major factors of the FAI are domestic chores, leisure/work, and outdoor activities. Wade et al. (1985) conclude that the FAI is a valid measurement of social survival. Thus, while assessing the functional independence of stroke survivors in public and domestic domains, such an assessment should concern itself not only with the FIM scores of the observed sample, but of their score on an instrument such as the FAI as well. With this in mind, the central research issue remains intact: Do such measures (FIM, FAI) provide a valid account of the actual daily experiences of stroke survivors who are living within the community?

**Understanding Lived Experience**

My concern for the daily organization of physical functioning for stroke survivors is rooted in Max Weber’s (1947) understanding of social action. In Weber’s methodology, there is always a selectivity of facts, highlighting the relativity of scientific investigation. In creating a system of sociological categories rooted in the subjective point of view (generating meaning and distinguishing normative patterns from the point of view of the persons whose action is being studied), the *ideal type* becomes the most important concept for sociological inquiry. Once the phenomenon is described in terms of a conceptual scheme, comparisons and generalizations are made through the categories constructed from scientific investigation. This is to say that generalization and comparison is made possible through the construction of ideal types, which themselves are constructed by understanding the point of view of those people being studied. This method of scientific conceptualization never fully reflects concrete reality, yet for Weber, it is the best possible method for the social sciences. There is actual meaning of a
concrete actor (Sinn) and there is the scientifically formulated pure type of subjective meaning (Verstehen), which is a general abstraction. Weber’s aim for social scientific investigation is to have the abstract meaning (insight into others) be as close to the actual meaning as scientifically possible.

However, Weber’s own studies (e.g. 1930) do not seem to adhere to his own methodological outline. Weber uses more of a historical comparative analysis than a subjective perspective that measures meaning in action. Weber’s own work may have been influenced by an understanding of knowledge that is closely linked with Kant. If understanding of the world is seen as the use of a table of universal categories in giving meaning to experience (conception shapes perception), then it follows that the primary challenge for social scientists is to understand the formulation of such universal categories (the comparative study of history, economics, and law to understand the formulation of Geist [mind]). While Weber outlined social action as being defined through meaningful behavior, he did not outline how the meaning of human behavior is concretely produced in everyday life.

In contrast, Alfred Schutz (1967), using Edmund Husserl’s phenomenology, sees the social world as always emerging, filled with social types of its own. To become aware of this emerging world requires a reflexive glance. This defines the world in toto as an unbroken stream of lived experiences. In order for an action to have subjective meaning it must be focused upon. This focus is produced through reflective action, or interpretation. Thus Schutz furthers Weber’s methodological outline by rooting the formulation of conceptual knowledge in everyday, or lived perception (perception leads to conception).
Schutz (p. 38) states that every meaningful interpretation of the social world is “pragmatically determined.” This suggests that people in their everyday lives interpret actions on their own, separate from research considerations. Schutz breaks down Weber’s concept of meaningful action into three key components. There is

- Intention: future, what will be
- Action: present, now; how what will be is accomplished
- Act: completed deed, past, meaningfulness of the accomplishment

This creates two distinct types of meaning (understandings) to action:

- The object meaning: the accomplished act
- The flow to action meaning: the immediate action of accomplishing

Life is composed of layers of meaning, which build up a world of experiences. From this outline one can see that the meaningful world is always action-in-practice. Schutz (p. 56) makes this clear: “Phenomenal experience is, therefore, never of oneself behaving, only of having behaved.”

If the sociological endeavor is, as proposed by Weber, to create abstract categories of meaningful action that are as close to actual personal meaning as possible, then the sociological study of a phenomenon such as stroke should measure people’s retention (accomplishing action) and reflection (accomplished act). Husserl distinguishes a primary remembrance as a primal impression (retention), and a secondary remembrance as a recollection, or reproduction. It is retention that makes the experience of time possible (the present now is different than the earlier now). Recollection on the other hand, is where such temporal perception becomes verified (memory, reproduction of a temporal object). Thus, lived experience flows, and all we can do is swim after it.
Experience runs off, and for lived experience to become meaningful a retrospective glance is required. In other words, intention becomes visible in the process of recollection/reflection. It is this understanding of meaningful behavior that Schutz implements into the methodological stance of Weber, marking a more precise understanding of how social science can achieve subjective understanding of people’s everyday worlds.

**Everyday Life**

A more recent extension of Weber’s methodological stance regarding social action can be seen in the work of Aaron Cicourel. Cicourel’s (1964) main concern is “linking the measurement of social action to inferences about social structure,” which Cicourel views as that of the practice of everyday life. Demographers, for example, are not faced with theoretical dilemmas when illustrating a decline or growth in population by using birth rate, age, death rate, and marital status, as indicators of population shifts (Cicourel 1974b). Measurement problems arise only when researchers are concerned with accounting for and interpreting social action, that is, when they strive for practical understanding of the facts in question. Cultural meanings may be seen as categories of understanding people use to orient, guide, and modify interpersonal exchanges. For Cicourel, the study of social action is the study of emerging, stabilized, altered, and destroyed belief systems. Cicourel (1964: p.197) adds, “A basic goal of sociology is the search for and measurement of invariant properties of social action within the context of a changing social order.” The major methodological pitfall for social researchers is to accept the generation, transmission, and understanding of meaning as self-evident. Doing so glosses over understanding how social actors go about making sense of their environment in socially acceptable ways. Further, “the researcher cannot assume that he
and the actor enjoy the same community of subjective meaning structures for assigning
cultural significance to an event or object,” (p. 199). These statements by Cicourel relate
to and help clarify my earlier discussion of using common assessment measurements as
scientific insight into everyday life, as well as relating to the example I provided
regarding the difficulties participants had in completing the GDS.

**Formal Assessment and Lived Experience**

The above statements by Cicourel also apply to the measurement of physical
functioning, where formal functional assessment and everyday functional capacity may
be at considerable odds. In the physical rehabilitation professions there is much focus on
the reliability of FIM scoring. Prior to being professionally certified as a FIM rater,
health practitioners are to receive structured training, performing scoring exercises and
ultimately passing a FIM scoring test, which is compared to the gold standard for
reliability (VAMC 1990). This gold standard consists of the scores achieved by a panel
of clinical experts in assessing various filmed scenarios, which are used for the
instructional exam. Universal functional assessment therefore relies upon the normative
standard of FIM scoring and analysis. Referring back to Table 1, those who are
discharged to the community as high functioning would appear to be similar in functional
capability at home and in public. This category of high functioning stroke survivors
seems to make up a group of like bodies in terms of impairment status.

The main issue is not that the FIM assessment is unreliable. The methodological
issue is that the clinical understanding of functional ability (gold standard of FIM
measurement created by an expert panel of health practitioners) may not be congruent
with the patient’s understanding (the lived experience) of physical impairment. Simply
having the patient fill out a 20-item life satisfaction scale and/or an activities index may
still fail to capture the complexity of difference found in those who rate similarly on the functional assessment measure. This is primarily due to the fact that all such measurements accept the generation, transmission, and understanding of meaning as self-evident. That is, by the nature of such universal scaling practices, they fail to capture the intricate complexity of varying social contexts. Fujiura and Rutkowski-Kmita (2001, p. 69) provide a nice summation on this point:

The act of classification and counting is far from a simple matter, often subject to methodological bias and the distortion of the cultural lens. Disability identification is a judgment on the human condition, and its statistical summary represents more than a simple enumeration of those who are disabled and those who are not. Herein lies the challenge in understanding the numbers – disability is a contested concept, and a critical evaluation of disability data must assume multiple personas.

In summary, this dissertation sets out to compare FIM and FAI assessments with stroke survivor narratives derived from qualitative interviews. Theoretically, this dissertation compares medical understandings of functional ability after stroke with the understandings expressed by stroke survivors themselves as they reflect upon their everyday lives. The primary goal is to present an in-depth understanding of what it means to survive at home after having had a stroke.
Talcott Parsons’ (1951) conceptualization of the sick-role provides an initial outline of the structural situation of the patient. Parsons notes that the sick role identifies the patient as helpless. Being sick is regarded as being a deviant, who is in need of professional, technical, competent assistance. Parsons (p. 441) makes a clear distinction between lay knowledge and expert knowledge, stating that “if he [the patient] were fully rational he would have to rely on professional authority, on the advice of the professionally qualified or on institutional validation.” Illness is seen as a situation of strain that presents complex problems for the person in terms of his expectancies regarding normal life patterns. The ill person adopts the sick role, which enables the physician to sufficiently penetrate the private affairs of the patient through minimizing resistance, allowing the physician to perform her function. Parsons sees the medical structure as an example of the overall social system, which minimizes complexity, enabling people to adequately function in their specified role, maintaining the equilibrium of the environment.

Foucault’s book, *The Birth of the Clinic* (1973) revitalizes the medical world through the concept of gaze, where people both see and say, forming an alliance between words and things. The medical gaze does not reduce the individual, but rather produces in him an irreducible quality.
Foucault (p. 3) begins by stating:

For us, the human body defines, by natural right, the space of origin and of distribution of disease: a space whose lines, volumes, surfaces, and routes are laid down, in accordance with a now familiar geometry, by the anatomical atlas.

Medical truth becomes exposed as knowledge in practice, where bodies are regimented in time and space by the construction of a specialized language produced in a specific physical boundary, the clinic. This knowledge then implodes into everyday life and becomes actualized in bodily practice. However, rather than expressing medicine as a perpetually changing flow of theories and systems, the history of medicine is recounted by its practitioners as a constantly stable experience (p. 54). This recounting style helps to mask speculation behind clinical evidence. The clinic knows its truth, but this truth changes through historical shifts and calculated exchanges. Whereas Parsons sees patient/physician interaction as encounters that are made predictable by the functional requirements of a stable social-system, Foucault sees the patient/physician interaction as regimented by the clinical gaze that hides its uncertainty behind an institutionalized discourse of expert knowledge. Hence, the medical system is not stable. We only say it is. “The sight/touch/hearing trinity defines a perceptual configuration in which the inaccessible illness is tracked down by markers, gauged in depth, drawn to the surface, and projected virtually on the dispersed organs of the corpse,” (Foucault p. 164).

Medical truth eventually becomes one of an invisible visibility [life defined by death].

While Foucault (1973) presents a history of the medical body, the body itself remains an object regimented by discourse (similar to Max Weber). Foucault’s thought however becomes more complex than this (Turner 1994), developing into a theory of the body that has a contradictory dual existence. Not only is the body the product of
discourses [which for Foucault are self-determined, independent of the speaker], but through private resistance to dominant knowledge structures via acts of deviance or perversion, the human body can transcend such discourses. Power is a product of society, resistance the product of the body. This corporeal resistance to power/knowledge, however, is seen as a playful exercise. That is, there cannot be an organized counter attack, for that merely replaces one power with another. The only real resistance is the free interplay of bodies and pleasures (Foucault 1978). Bryan Turner (1984, p. 250) believes that due to his abandonment of the body as sensuous potentiality, Foucault does not provide an adequate phenomenological account of the body. Turner suggests that embodiment is more than a concept; it is also a potential. Therefore, rather than presenting a theory of the body, it may be suggested that Foucault presents a theory of anti-bodies (Turner 1994) that can repel unwelcome intrusions only by playing with knowledge structures. This is demonstrated by a body that refuses to recognize such structured knowledge (discourse).

In deciding that Foucault fails at providing an adequate account of bodily potential, Bryan S. Turner (2000) presented an alternative view of how to study the body as potential by making a clear distinction within the philosophy of medical science. There is the clinical entity (a pattern observed by a health practitioner in interaction with a patient), and a disease entity (‘knowledge about’ a condition produced by lab tests, observations, and other information). A medical textbook deals primarily with theories regarding disease entities (Turner 2000). The clinical condition remains relatively constant so that what Hippocrates observed as the mumps is generally what is observed as the mumps today (reliability issues). The clinical reality of disease can be handed
down through the generations while theories regarding health and illness shift with changes in social values, circumstances, and fashion (validity issues). Outlining how medical-professional meanings of health and illness change through time and space (e.g. Foucault 1973) may also suggest that clinical assessments of functional independence are socially produced. Such a suggestion, however, does not suggest that medical understandings of health and illness are completely disembodied. Rather, such a statement indicates that the meaning of a functional independence score is mediated by the training of those who are assessing the body (rating that is reliable in comparison with the gold standard), and that such assessors are products of a specific medical culture (rehabilitation profession of the late 20th/early 21st century). This is to say that the conception of functional independence, and the potential of the body, can change radically, depending upon how it is being taken into account.

**Knowledge of the Body**

This brings us to the question of medical knowledge of the body. In particular, the question that becomes paramount is how medical knowledge relates to the lived body. Sally Gadow (1982) considers the lived body in impressive detail. The medical view of the human body culminates into complete abstraction. Gadow (p. 86), in contrast, presents a dialectical progression that begins with the lived body (primary immediacy), followed by the object body (disrupted immediacy), then the harmonization of the lived body and the object body (cultivated immediacy), finally progressing to the subject body (aesthetic immediacy) of aging and illness. The lived body becomes actualized in interaction. A distinction is made between one’s self and the world (unity/environment). One can have an effect upon the world, but also be affected by it. In primary immediacy self-body are unified. Once the self-body experiences itself being affected by a part of
itself, the self-body unity becomes divided. This marks the progression into disrupted immediacy. The body is now unified with the world, with body and self acting upon one another. Where the lived body is immediate, the object body is constrained. The body becomes aware of its ineptness. The body now is expected to serve the will of the self, but alas, it can rebel, refuse to function, reversing the master-slave roles. The dialectic at the stage of disrupted immediacy is experienced as one of constant struggle. The self controls the body via discipline and training, or is controlled by the body due to illness or disability.

At the stage of cultivated immediacy, the body and self become reunited yet remain experienced as distinct. The body is seen as necessary to the self in order for the self to reach its full development. Through the training of the body, the self has learned some new actions. These learned behaviors now become immediate acts, not trained, representing a new unity between body and self. This new unity, however, remains representative of the oppositional nature of the body-self relationship found in disrupted immediacy. The body continues to be experienced as an instrument that is determinant only when it limits the self. The body is still not experienced as a subject capable of generating its own meaning, but rather remains an object for the self. Gadow (p. 93) suggests that perhaps this way of understanding the body-self dialectic is partly why aging and illness are viewed as negative experiences. With such a unilateral understanding, the body increasingly becomes an obstacle for the self. The body is experienced as our self-oppressor, destroying self-possibilities through breakdown of the object body.
As Gadow explains, it is only through experiencing the body as subject that the body-self unity becomes fully developed. The subject body is part of the self, capable of offering its own aims, purposes, and meanings. Once the body is experienced as subject, the body-self dialectic is no longer based on mastery or submission, but rather on intrasubjectivity. The body becomes recognized as a manifestation of selfness. The body is no longer subjugated to the will of the self. At the stage of aesthetic immediacy the body and self become experienced as mutually related. This intrasubjective recognition of the body-self is often not recognized until one has reached the latter stages of adulthood. The importance of aesthetic immediacy to understanding the body-self dialectic in regards to functional independence after stroke is summarized by Gadow (p.96):

The subject body in illness and aging speaks an unfamiliar language. For its communication to become lucid, development is necessary on all sides: other parts of the self must learn how to perceive and interpret the body’s symbols. That learning, of course, is the opposite of the training imposed upon the body by the self during the process of mastery. Now, the self must learn to attend and must acquire complex ways of responding.

Once the body is experienced as subject, the body is no longer understood through a fixed, pre-determinable trajectory. This understanding of the body-self dialectic in illness and aging illustrates the inadequacies of bio-medical language when attempting to describe bodily experiences (and thus, bodily potential). The reality and meanings of the subject body are as infinite as is the self (that is, bodily potential is limited only by the self), transcending the logical possibility of a completely determinable understanding through objective examination. Gadow concludes that the best way of understanding the subject body is to understand it as aesthetic object. This way of understanding the subject body allows one to understand the body as developed, but also as an object free to
develop further (sensuous potentiality). The body becomes valued in its wholeness, with the facts of the body understood as symbolic experience rather than as objective, universal truths. Understanding the body as aesthetic object places scientific focus on the many ways people shape themselves in aging and illness. The stroke recovery experience involves understanding how the body expresses itself in everyday realities, ultimately resulting in refined forms of scientific concern for those surviving after stroke.

Drew Leder (1990) suggests that the typical lifestyle within American society is one of disembodiment. We become increasingly separated from nature, with most of our physiological needs met prior to us reaching a level of distress. Where in the past the physical body placed limits upon us, today new technologies of rapid communication and transportation have largely ameliorated such physical constraints. Leder finds many of our activities such as yoga, or gym-work as a reaction to such disembodiment. In a disembodied lifestyle where our physical nature seems to be unproblematic, the body seems to disappear. This is to say that the body appears to be absent in the acting-out of many daily activities.

The strongest presence of the body comes in times of dysfunction when the body itself must be dealt with (such as the experience of pain causing the body to dys-appear). This leads to the absent body as being experienced as the desired, normal state, and the present body being linked with abnormality and undesirability. The presence of a painful body is an alien presence that puts harsh demands upon the self (p.87). This creates a split between the self and an alienated Other. Such a split is representative of Cartesian dualism. Leder suggests that this split be mended to form one body. Our culture is shaped in response to bodily needs and desires (food, shelter, sexual regulation) and in
turn bodily practices and understandings are shaped by existing within the parameters of certain social structures. For Leder, what is required is a breaking-free of a dualistic understanding, allowing for a reclamation of the lived body. Leder uses the Chinese concept of ch’i, adding (p. 158): “As the world exists only in relation to the experiencer, so the experiencer exists only in relation to the world.” Reality is an inseparable intertwining of body and world. Leder suggests that forming one body between the self and Other requires compassion. Through compassion, the body is not overcome, but rather unified with all others.

Thomas Csordas (1994) states that anthropologists generally see the body as the material artifact (an object) of culture and history. The body centers and locates self and culture at that particular point in time (the object that locates the subject). Within medical worlds the body is also an object, a representation, but a very specific object that must be worked on in hopes of bringing it back to normal. It is the body as subject, however, that is experienced in the sensual, experiential world of everyday life. This sense of existential immediacy, this fundamentally conditional experience, is referred to as being-in-the-world. Our being-in-the-world can be disclosed through language. Csoradas, however, warns against envisioning the body as text, which seemingly relegates the body into the form of a passive sign (yet another object). He suggests, rather, we see the body as positioned complementary to the text. Doing so creates a new, dialectical relationship between text and textuality (object and potential). Exploring the world in these terms enables one to ground a theory of culture and self in embodied experience.
In an extensive review of anthropological literature on the body, Margaret Lock (1993) finds that historically, many researchers have set the body aside. Generally, she finds a social scientific ambivalence towards the body, at least until the late 1970s. Lock states that research which deals with the politics of producing and reproducing bodies brings a radical position regarding the truth claims of medical and epidemiological sciences. The value of this research is believed to be the improving of dialogue within scientific knowledge, where theory is reconciled with practice, and the subjective body is brought into relation with biology and society. Lock (p. 139) comments: “ethnographic accounts in which olfaction, taste, sound, and touch take center stage have opened up new horizons, with great potential for a politics of aesthetics grounded in felt experience.” Lock concludes (p. 148) that: “despite increasing pressures we should, I believe, resist all pressures from the Other to produce tidy answers and ‘Just So’ stories, remain eclectic in our approach, and be content with a body that refuses to hold still.” This body that refuses to hold still is more readily experienced once the interactive, relational, and social aspects of the body are emphasized within an understanding of the embodied agent (Lyon and Barbalet 1994).

**Knowing the Disabled Body**

You will see me walk as far as the door, I will take two steps, and then stop to catch up with myself… if I walk with someone in the street I take his arm; I don’t need a cane, but I must hang on to someone… When I am by myself I have a cane; I don’t really limp, but I lurch along because I don’t have my balance. Well, you see, I have always been active, I loved to dance, I loved to ski, I loved to go all over the place. The other day there was a party to which I went, I danced a slow, two slows… I can still dance the slow but, you know, that’s not a whole lot. [former taxi driver with multiple sclerosis, age 48]¹

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Albrecht et al. (2001) define disability as both a private and public experience that redefines one’s life in negative and/or positive ways. As medical technology helps to increase the average lifespan, all families are more likely to come face-to-face with disability. The way that disability is conceived of and responded to is dependent upon how one’s daily life is framed (Goffman 1974). In current disability studies it is generally understood that in order to understand the disability community the voices of those who make up such a community must be included in the professional discourse. As Albrecht et al. (2001 p. 2) ask: “Who are disabled people, and who should speak for them?” Disability studies as a field is concerned with the inclusion of multiple perspectives, and integrating these multiplicities into continually more sophisticated understandings of disability issues.

Braddock and Parish (2001) distinguish disability from that of impairment. The term impairment relates to a biological condition, while disability is intimately linked to larger social contexts. Thus, in reference to the above extract (p. 25), the diagnosis of multiple sclerosis (biological disorder) relates to physical impairment (loss of motor coordination). On the other hand, in discussing his everyday life, the impaired person presents us with some of the social limitations faced by someone living with such impairments. That is, the physically impaired person does not simply focus on the biological aspects, but rather incorporates social realities into his reflections on what it means to live with a particular disorder such as multiple sclerosis. In discussing social limitations, the speaker is conveying to us what it means for him to be disabled. Social limitations therefore, construct the meaningful differences between the able-bodied and the disabled-bodied (Davis 2000).
Fujura and Rutkowski-Kmita (2001) discuss three broad systems of classifying and defining disability. There are impairment-based schemes that focus on organ malfunction (medical model of disease/injury), functional limitation or restricted life-activity schemes that focus on functional loss (which if restricting a given social role results in disability), and ecological perspectives which center around the concept of social disadvantage (handicap). It is further noted that functional limitation schemes are very common in current national health surveillance systems such as the UDS. Particular to the current study, the FIM and FAI can be seen as examples of measurement scales commonly utilized in such a functional-limitations perspective. Ecological schemes were introduced into large-scale disability assessments primarily to incorporate environmental context with lack of functional capacity. With heavy critique of a linear model where disorder leads to impairment which leads to disability which leads to handicap, revisions were made which represented simultaneous dimensions of disablement (Fujura and Rutkowski-Kmita 2001). Currently the International Classification of Functioning, Disability and Health uses the terminology of body functions, body structures, activities and participation, and environmental factors. Body functions and body structures illustrate the medical model (scheme 1) of disease and injury classifications. Activities and participation illustrate the functional limitations perspective (scheme 2), with the ecological perspective being covered under the classification of environmental factors. This new classification system no longer relies on a distinction between disability and handicap that many found to artificially separate the measurement of restricted activity from social context (Edwards 1997).
The World Health Organization endorses the use of the ICIDH-2 (International Classification of Impairments, Disabilities and Handicaps, Version 2), publicly urging research sites to use this classification scheme. With virtually every classification scheme and way of categorizing life experience incorporated into the ICIDH-2, the issue then shifts to constructing a particular implementation method and producing valid result analyses across studies that may be oriented to different components of the classification system. For example, under the rubric of activities and participation there are 9 different major categories:

- Learning and Applying Knowledge: purposeful sensory experience, basic learning and applying knowledge
- General Tasks and Demands: organizing routines and handling stress
- Communication: receiving and producing messages, carrying on conversations
- Mobility: transferring from one place to another, walking, running, climbing, and using various forms of transportation
- Self-Care: washing/drying one’s body, dressing, toileting, eating, and drinking; looking after one’s health
- Domestic Life: everyday actions and tasks, ability to provide shelter, food, and clothing, household cleaning and repair, caring for personal and other household objects, and assisting others
- Interpersonal Interactions and Relationships: basic and complex interactions with people in a contextually and socially appropriate manner; these can be general or particular interactions with family members, other relatives, friends, lovers, or strangers
- Major Life Areas: carrying out tasks and actions required to engage in education, work, and employment and to conduct economic transactions
- Community, Social, and Civic Life: tasks and actions required to engage in organized social life outside the family; this may be community life, recreation and leisure, religion and spirituality, human rights, political life and citizenship, or other relations
Compare the above outline of activities and participation to the following outline of environmental factors. There are five major categories under this rubric:

- **Products and Technology**: a wide variety of devices used in public and home environments.

- **Natural Environment and Man-made Changes to the Environment**: population, flora and fauna, climate, natural and human events, light, time, sound, and air quality.

- **Support and Relationships**: people and animals that provide practical physical and/or emotional support, such as nurturing or protection; the environmental factor is not the supportive person or animal but rather the actual physical and/or emotional support that is provided; this includes family, friends, community members, neighbors, peers, people in authoritative and subordinate positions to the individual, domesticated animals, health professionals and strangers.

- **Attitudes**: ideologies, customs, values, norms, as well as factual and religious beliefs; these are the attitudes that are external to the person; they may be positive attitudes of respect, recognition and trust as fellow human beings, or negative attitudes of stigma, stereotyping, marginalizing, and/or neglect.

- **Services, Systems and Policies**: first component consists of services and benefits provided, second component is administrative controls that organize, monitor and control the goods and services provided in component 1, and the third component consists of the policies, rules, and regulations that govern and regulate the systems that make up component 2.

Large-scale surveillance often demands definitional simplicity, but the above breakdown of two major components to the ICIDH-2 illustrates an enormous amount of multidimensional complexity. While the World Health Organization continues to attempt to construct a valid instrument that captures the various components related to disability, designating how this instrument can and should be administered, creating a universal instrument that captures the full-range of human experience seems more and more methodologically improbable, particularly as disability definitions shift further towards contextually specific interactions.

In terms of large-scale assessments, measures that capture interactions with social context or environmental setting are relatively unexplored (Fujura and Rutkowski-
Kmitta 2001). Fujura and Rutkowski-Kmitta (p. 91) also note that “the utility of the data is directly related to how well individual variance is accounted for.” Global assessments of disability may become somewhat effective when findings are limited to general headcounts, or percentages of type-specific impaired, disabled, or handicapped people living within the overall population. When dealing with the everyday meanings of disablement, the complexity of such understandings go beyond the compass of scaling instruments. Scaling instruments and population assessments aggregate data prior to analysis, thus always limiting (the purpose of using a measurement scale rather than in-depth interviewing techniques) and oftentimes ignoring complexity (result of treating the measurement scores as universal values).

The benefits of standardized measurement and generality are chosen over the benefits in understanding the details and complexities of everyday life. The problem in measuring disability quantitatively is that generality fixes people into specific categories (e.g. high functioning stroke survivor) whereas stressing the importance of social context indicates the fluidity of limitations, even when considering the same impaired body. As disability researchers (Zola 1993) have been wondering for some time now: what exactly do the numbers tell us? The above discussion regarding the disabled body leads into a brief presentation of conceptual frameworks and symbolic models of disability. The Nagi (1965) model is illustrated by Granger (1984) in Figure 4-1. Altman (2001), however, presents the Nagi model in such a way that it incorporates the more social aspects of role and behavior influenced by reactions and expectations of others.
The Nagi model is of interest because it was first presented at a conference co-sponsored by the American Sociological Association and the Vocational Rehabilitation Administration as an attempt to illustrate the usefulness and applicability of sociological theory and research for the field of rehabilitation (Altman 2001). Although not clearly specified by Nagi (1965), from a sociological standpoint, the addition of interactions with others as seen in Figure 2-3 would seem to be an important aspect to disability studies. Granger (1984) uses the Nagi model to illustrate the first attempt at developing a functional perspective in disability studies. Granger also illustrates a model proposed by Wood and Bradley (1978) that reduces the importance of functional limitations, highlighting the impact of impairment and disability. It is this model that the World Health Organization originally adopted in 1980:
Granger’s own model (1984) is specifically designed to illustrate functional assessment in rehabilitation. While, at least graphically, more complex than the above models, Granger incorporates the Nagi and Wood and Bradley models into his conceptual framework. Granger breaks down three components to data analysis: 1) impairment at the organ level, 2) disability at the person level, and 3) handicap at the societal level:

**Conditions**

<table>
<thead>
<tr>
<th>Pathology</th>
<th>Behavioral</th>
<th>Role assignment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anatomical, physiological, mental and psychological deficits determine</td>
<td>Performance deficits within the physical and social environments contribute to</td>
<td>Environmental and societal deficits influenced by social norms and social policy create</td>
</tr>
</tbody>
</table>

**Key terms**

- Impairment (Organic dysfunction)
- Disability (Difficulty with tasks)
- Handicap (Social disadvantage)

- Limitations in using skills, performing activities, and fulfilling social roles

**Analysis**

- Selected diagnostic descriptors
- Selected performance descriptors
- Selected role descriptors

**Functional assessment of abilities and activities**

**Interventions**

- Medical and restorative therapy
- Adaptive equipment and reduction of physical/attitudinal barriers
- Supportive services and social policy changes

All needing long-range coordination to improve and maintain functioning

Figure 2-4. Granger's Nagi/Wood and Bradley model

The last general disability model presented is the most recent World Health Organization Model, based on the ICIDH-2. The conceptual framework from which I have organized my current data analysis of stroke recovery is based on the WHO model represented in Figure 2-6.
In looking at the Granger (1984) model in Figure 2-5, it can be stated that the current dissertation research focuses on behavioral conditions that contribute to difficulty with tasks (disability). I am comparing the performance descriptors utilized in common rehabilitation assessments of stroke recovery (FIM and FAI) with the accounts provided by actual stroke survivors who are living in a community-based setting, primarily those residing in a one family household. Further, I am attempting to illustrate the relation of such performance descriptors to the everyday lives of certain (male veterans; high functioning) stroke survivors. My working conceptual framework illustrated in Figure
2-6 provides detail into how I see stroke, physical functioning, activities of daily living, social interaction, the natural environment, and personal demographic variables interrelating in the everyday lives of stroke survivors. My interpretation is based on the ICIDH-2 model developed by the World Health Organization. The medical assessment of stroke is determined by the reported etiologic diagnosis generated by the local VA. The FIM is a measure of physical functioning, the FAI a measure of activities of daily living. The personal accounts provided by stroke survivors, as well as the demographic data generated for them, will enable me to outline the conceptual schemes of social interaction, environment, and personal factors, as well as further assess physical functioning and activities of daily living within specific domestic and community contexts.

**Illness as Lived Experience**

Up to this point in the report I have outlined the FIM and FAI measures, discussing the benefits and limitations of such general measurement scales. I then related this discussion of measurement to more theoretical issues regarding medical discourse and disability theory and their respective conceptualizations of the human body. Next, I will discuss the use and usefulness of personal accounts in disability studies. In particular I will use the literature regarding chronic illness to highlight the importance of qualitative data analysis in understanding stroke recovery. I then will review the major qualitative studies of stroke survival.

Kathy Charmaz (2000) noted that while health researchers, practitioners and policy makers claim to represent patients’ concerns, in-depth interviews of the patients’ experiences are rarely incorporated into systematic analysis. Obtaining such interviews with patients enables researchers to integrate the illness experience with other styles of
scientific assessment practices as a way to obtain deeper insight into how people view themselves as ill (e.g. as a stroke survivor) as well as how the illness impacts their everyday lives. Medical professionals define disease; patients define illness (Charmaz 2000; Conrad 1987). Charmaz (p.277) helped to clarify this point: “Through analyzing the experience of chronic illness, we learn what chronically ill people’s actions mean, when and how they come into conflict with practitioners, and what it means to face loss and reconstruction of self.”

Arthur Kleinman (e.g. Kleinman 1988) illustrated how personal reflections on illness can provide scientific researchers with useful information regarding the meaningful experience of life on the margin (when the body dys-appears) in terms of human health. As Kleinman pointed out (1995, p.8), “I, like many others, doubtless including [Clifford] Geertz himself, have become less impressed by systematic connections and more by differences, absences, gaps, contradictions, and uncertainties.” Kleinman states that one of the goals in his own research is to deepen the study of a symbolic bridge that links people with each other as well as to local social systems. This is done through the use of somatization as a centralizing concept. Kleinman sees the body as mediating between personal and collective experience.

Chronic illness, for example, is often seen as a disruption in people’s lives (Becker 1997; Bury 1982; Charmaz 1991). While the illness may present a crisis in the person’s life, the illness itself is seen as a temporary condition that is to be battled against and defeated. There is hope for a healthy future, even a continuing belief in recovery despite dire medical prognoses. Ill persons have little understanding of chronic, prolonged states of illness or permanent disability. People often view illness as something that is not part
of their self. It is something outside of who they really are. In time, many believe, they will return to normal. Such an understanding of illness may lead medical practitioners et al. close to the chronically ill person to believe they are in denial of their actual condition. Charmaz indicates that the label of denial is often stretched to fit a certain agenda, usually of patient compliance. Once a person receives a specific diagnosis, she is often left to learn about its meaning on her own. There is an ambiguity to the expected outcome of specific diseases and conditions, where the boundaries between acute and chronic illness become blurred. With such uncertainty, when giving meaning to their health state many chronically ill people choose the most optimistic prognosis.

It seems that as long as there is time, there is always hope. With time, however, also comes personal learning about chronicity. People begin to learn that their illness affects their daily life, and so personal adjustments must be made (Bury 1982). The illness must now be managed more than battled against. As Charmaz (1991 p. 21) indicated, “the meaning of disability, dysfunction, or impairment becomes real in daily life.” Once daily routines become tested, the altered body begins to become realized. Rather than face this, some people retreat, staying in bed for long intervals throughout the day, perhaps in an attempt to wait out the illness. For many others, their illness must be redefined as a new part of who and what they are.

In particular, stroke occurs with sudden onset. The reality of stroke survival is not a universal experience. The beginning of living after stroke is a jarring to the body, while it’s aftereffects represent a wide range of severity. There are many social as well as biological factors that impact the level of intrusiveness the stroke has on a person’s normal life. Along with the severity of the cerebral-vascular accident, there are many
everyday factors that influence the recovery path survivors travel. These differences in experience, however, tend to become marginalized in assessing the rehabilitative process. Kaufman and Becker (1986) outlined the criteria of rehabilitative treatment that stroke survivors must conform to in order for them to be seen as candidates for such treatment. Because of federal reimbursement regulations, stroke patients are commonly discharged to the community prior to full rehabilitation. Occupational and physical therapists note this insufficient time as a major impediment to full recovery. With such time constraints, a general functional independence assessment is commonly seen as the best that medical practitioners can do. Kaufman and Becker (p. 987) add: “Functional independence has been created as a substitute for health… Functional independence is the most they can offer patients.” The structure and regulations of the American health care system preclude optimal rehabilitation for stroke survivors. Furthermore, stroke rehabilitation is not seen as part of mainstream biomedicine. The rehabilitation process itself is a marginal medical practice, further limiting the resources provided for adequate recovery in terms of meaningful daily experiences. This places the majority of burden or reaching meaningful recovery upon the chronically ill person, after they have exited the medical environment.

Nancy Doolittle (1992) examined stroke survival as a progressive experience of bodily recovery. Doolittle noted that after experiencing a stroke, people are confronted with arms and legs that no longer work in an automatic fashion. There is a persistent dialogue between mind and body. Affected limbs are heavy and cumbersome, with the control of the body requiring a great deal of effort. The body becomes highly objectified, with affected limbs being seen as objects that must be consciously manipulated. For
stroke survivors, the primary adaptation is bodily control. A lag of improvement, or recovery plateaus, can become extremely frustrating for stroke survivors. There is a re-recognition of bodily capacity and possibility, which is accomplished via experimentation in daily life. Such experimentation is an ebb and flow of renewed hope (physical success) and renewed disappointment (physical failure).

Gay Becker (1997) related the stroke experience to being thrown into chaos. It disrupts the person’s ongoing biography. The sense of order that the person had in their life story disintegrates, forcing one to reconstitute their life. Whether or not the person is deemed morally responsible for the onset of the chronic illness, he is constantly seen as being morally responsible for getting back to normal, or at least getting as close as possible to his prior state of normalcy. If one’s attempt to restore everyday, lived order is seen as hopeless, then the effort to recovery may be specifically affected. If one’s attempt to restore order in their everyday lives is seen as hopeful, then the effort to recovery may take a different course. However, as should be seen from the current review of the literature, recovery paths are often not as linear as the following of one or the other. A recovery experience often shifts from one of hope to hopelessness, and back again. The experience of recovery is intertwined with the experience of being-in-the-world. For Becker, order must be imposed, and the way one’s life is ordered is dependent upon what metaphors are used in actively constructing the story of one’s life.

For example Doolittle (1994) presented a poignant paradigm case of the lived experience of stroke recovery. A few days after having a stroke, one of Doolittle’s participants, Mr. Rowland, is stunned and discouraged by his stroke experience. With an oncoming important event (son’s wedding), however, Mr. Rowland works hard at bodily
recovery so that he can reach his personal goal of walking onto the airplane he will take to the wedding. Not only does Mr. Rowland succeed at this, but he also dances at the wedding, with friends and relatives clapping at his performance. Later on in the recovery process, however, Mr. Rowland speaks of wanting to hide from his friends and no longer wants to live. His recovery has reached a plateau, and Mr. Rowland is now dealing with this experience in his everyday life. Doolittle (p. 216) noted that medical practitioners often see the fulfillment of recovery potential as the attainment of functional independence, measured by objective goals such as buttoning a shirt, self-grooming, or walking down a hallway. This focus, however, frequently differs from people’s lived, everyday realities. While functional independence may be seen as achieved, the progress of meaningful activities may be absent in medical assessments. Doolittle sees the work of recovery as the conscious attempt to regain participation in meaningful activities. Patients feel that coherent bodily knowledge must be recaptured, attempting to make life now as close as possible to life before the stroke. Doolittle (p. 223) concluded: “therapy strategies that treat personal concerns and meanings as paramount and that take into account social context will best assist the person to experience progress and recovery post-stroke.”

Ellis-Hill et al. (2000) used a life-narrative approach in understanding physical recovery after stroke. Focusing on interviews conducted with 8 stroke respondents and their spouses in-hospital, six-months after stroke and 12 months after stroke, the major themes identified were fundamental life change and the experience of self-body split (p. 727). The stroke experience was related to entering a foreign world with a sense of not being able to get back to where one once was. As one account notes, a stroke survivor
may come to think of themselves as only half a person. The stroke experience is more than simply managing one’s body. It embraces and challenges the person as a unified entity (leads one to question her own lived potential). This is to say that the stroke experience embraces and challenges one’s full personhood (Luborsky, 1994).

It was noted at the end of Chapter 1 that this dissertation compares medical understandings of functional ability after stroke with the understandings expressed by stroke survivors themselves as they reflect upon their everyday lives. This chapter has presented a literature review beginning with Parson’s sick role, where the body is simply made compliant through adhering to a functional social structure, to Foucault’s medical gaze, where the body is constantly observed, tested, and measured by a knowledge that itself cannot be seen, to more phenomenological understandings of the subject body, where body and self split after a major illness, and then are reunified into a new, embodied self. The object body and subject body, as discussed in the current chapter are primary concepts in this research. Specifically, narrative data presented in Chapters 5 through 9 serve to present the ways by which stroke survivors experience the continual interaction of body-self-world, or what Thomas Csordas refers to as being-in-the-world. The next chapter outlines the method and research design by which I plan to present stroke survivors’ lived experience.
CHAPTER 3
METHODS

The current study focuses upon the activities and participation of stroke survivors who have returned home. In analyzing people who have had a mild stroke and were rated high in physical functioning at discharge and one month after discharge, I am analyzing a group that health professionals generally treat as homogenous. As stated in the previous chapters, my primary research questions are:

- What insight do measures such as the FIM and FAI provide researchers and medical practitioners regarding functional status of stroke survivors in home and public settings?
- Are stroke survivors who are categorized in the same recovery category really having a similar recovery experience?
- Do such measures (FIM, FAI) provide a valid account of the actual daily experiences of stroke survivors who are living within the community?

This study will collapse the mind/body duality, as well as decenter corporeal knowledge, through a view of the body in interpretive practice. It seems that the only plausible way of doing so is to go out on the margins of experience, playing witness to transformation in action.

Studying The Stroke Experience

I have been able to do this research thanks to work supported by the VA Office of Research and Development, Health Services Research & Development Service and Rehabilitation Research & Development Service. In particular, I am indebted to Dr. Maude Rittman, principal investigator of the larger multi-site study, *Culturally Sensitive*
Models of Stroke Recovery and Caregiving After Discharge Home. It is from this larger 4-year study that the data for this dissertation were obtained from. The study was approved by the University of Florida Health Science Center Institutional Review Board and the North Florida/South Georgia Veterans Health System subcommittee on the protection of human subjects. Informed consents were obtained on all participants. I served as one of many data collectors for the larger study. In addition to this, I took part in the qualitative research team meetings and the qualitative coding of interview data. The qualitative research team is an interdisciplinary team consisting of Dr. Maude Rittman (RN), Dr. Christine Williams (RN), my dissertation chair Dr. Jaber F. Gubrium (sociology), Dr. Mary-Ellen Young (rehabilitation counseling), and myself.

Kelly J. Devers (1999, p. 1155) noted that, “clinical, organizational, and policy decision makers’ need for knowledge and information in new and rapidly evolving areas are increasing the demand for qualitative research.” As more people live longer lives, not only surviving but living in the community after experiencing major health events such as stroke, a more thorough understanding of the lived experience of surviving such health events becomes an important goal for society. Charles C. Ragin (1987) points out that in social research, goals are primary. Methodological strategies follow goals. Ragin distinguishes between case-oriented and variable-oriented research. Case-oriented research focuses on a smaller sample (usually between 1 and 50), selecting cases that are theoretically significant. In contrast, variable-oriented research is primarily concerned with specifying general patterns across a population, which demands a larger sample size. Through statistical procedures, variable-oriented researchers may be able to reliably (at least to some degree) predict variable relationships within a population, but if these
variables have limited meaning in the everyday lives of the people who make up the population, how can we claim practical relevance of the results?

This question again raises the important social-psychological issue of how members of a given population [e.g. stroke survivors] take into account certain phenomena [physical functioning] in everyday lived experience. Rather than anchoring the primary research questions in terms of prediction, the questions highlighted in this dissertation are anchored in the concern for making the facts understandable, or meaningful, to the everyday lives of people involved in the stroke recovery experience. In attempting to study stroke recovery in-depth, this dissertation research adopts a case-oriented approach. Methodologically, in order to answer the three research questions stated at the beginning of this chapter in a satisfactory manner, I must compare the formal accounts provided by FIM and FAI data with how the stroke survivors themselves manage and take into account their physical functioning and activities in everyday life. Survivor accounts are interpreted from semi-structured qualitative interviews conducted in their home one month after discharge.

The population for this study consists of 31 veterans who were recently hospitalized with a diagnosis of acute stroke and discharged home. Such criteria exclude low-functioning persons who require long-term institutionalized care. Still, as will be seen in the chapters that follow, those who participated in this study vary in terms of their level of physical functioning in specific areas such as walking and dressing, as well as in their functional activities, such as watching television or dancing. It has been suggested (Rubenstein 1993) that 20-30 cases per category are adequate for saturation. 24 out of the 31 cases analyzed make up the category of high functioning stroke survivors. I have
included all of the participants who were rated below 108 on the FIM, using these survivors as a comparison group to my major category. This comparison group comprises the additional 7 cases. In Chapter 4 of the dissertation each of the 31 participants is described in detail in terms of demographic information, etiologic diagnosis, FIM score at discharge and one month after discharge, and FAI score at one month after discharge.

**Methodological Considerations**

One limitation to the study is that all of the participants are males who seek treatment at a Florida Veterans Health System Health Center. From this limitation, issues regarding the generalizability of the results arise. Typical criticisms of qualitative research such as the subjectiveness of data analysis and lack of generalizability of the results must ultimately be addressed via the accumulation of research findings (Ragin 1987). The research of Becker (1994), Becker and Kaufman (1986), Doolittle (1994), Ellis-Hill et al. (2000), and Kaufman (1988), all of which differ from the gender-weighted and criteria-specific (veterans, VA employees) issues of this research, can be compared with the findings derived from the current dissertation project. To make such comparisons would take more of a post-positivist viewpoint (Lincoln and Guba 1985), emphasizing the transferability of results (extent to which findings can be transferred to other settings). From the analysis of interview data collected for this study and comparing this data to previous research (which includes people living in different regions of the country, women, and non-veterans), the current findings of this dissertation appear transferable beyond male veterans who are currently living in a specific southern state.
As previously noted (Ragin 1987), the sample size for case-oriented research such as this usually ranges from 1 to 50. The purposeful sampling technique (Patton 1990) employed for this research was drawn from the criteria participants met for the larger cohort multi-site study (40 participants in each of 3 sub-categories; non-Hispanic white, African-American, and Puerto Rican Hispanic). Data analysis occurred simultaneously with data collection. Data collection was continued until data analysis became saturated, that is, until no new themes emerged from the newly collected data.

Guba and Lincoln (1994) contend that all scientific paradigms are human constructions and subject to human error. Advocates for a given paradigm must use persuasion to illustrate the utility of their position rather than claiming to present proof that a given position is true and all other positions false. Guba and Lincoln conclude that there is no indisputable evidence in social scientific paradigms, but rather researchers must rely on persuasion and demonstrations of utility in getting their points across to audiences. Rather than setting up my research design in such a way that it attempts to replace one persuasion (scaled measurement) with another (qualitative interviewing), I have attempted to follow in the tradition of Aaron Cicourel in seeing social science as an attempt at achieving a literal correspondence between what we believe to be the structure of social reality and the actual events and social objects we are measuring. The belief that science relies on hypothesis testing, that verification of research hypotheses is reliant upon numerical analysis, and that generality of findings can only be achieved via probability sampling techniques, is itself reliant upon some fairly precarious assumptions when relating such scientific beliefs to the understanding of human worlds. The major assumption that such beliefs must rely upon is that there is a social world that is
determinable beyond time, place, and the people who are actively producing it. That is, one must believe universal truths (social facts as things) exist beyond the context in which such truths are produced. My point of departure from this assumption follows that of Clifford Geertz (1973, p. 5):

Believing, with Max Weber, that man is an animal suspended in webs of significance he himself has spun, I take culture to be those webs, and the analysis of it to be therefore not an experimental science in search of law but an interpretive one in search of meaning.

Another common assumption in social scientific measurement is one that I discussed earlier; that the meanings possessed and generated by the researchers regarding certain phenomena are the same meanings participants possess and generate. This assumption relegates sociology into the realm of a folk discipline (Pollner 1987) where understanding the world relies upon unquestioned common sense that each object under study has a meaning which is shared by all concerned.

Guba and Lincoln (1994) call for a continual dialogue among all the various paradigm components. This is how I see my work; as a dialogue among all interested groups, including health care practitioners, medical sociologists, stroke survivors, as well as the author (me) and the reader (you). I believe this to be the best way of reconstructing reality (Schwartz and Jacobs 1979). The framework presented in Figure 2-6 is a working framework that has guided what I am looking for, and what I am comparing with what. Glaser and Strauss (1967) refer to this method as theoretical sampling. While such theoretical sampling and simultaneous data collection and theoretical coding seem to suggest a grounded theory approach, there is not only a theoretical framework established a priori based on the ICIDH-2, but there are other
theoretical concerns that orient my research endeavor, beyond the recorded text provided by the participants.

Earlier, I discussed the relation of Weber and Schutz to my sociological viewpoint. Furthermore, following Cicourel (1967) I have attempted to base my analysis of the real world of stroke recovery by examining the routine practical activities in the everyday lives of those living in the actual world I am studying. I have not already decided what the real world is all about, but rather I am attempting to study how the world of stroke recovery is produced in the reflections offered to the data collector by the active member of that world. I am interested in how certain members of the stroke recovery world themselves specify sequences of activities and signify recent events. This is provided through personal narratives that provide information regarding what is happening since they left the hospital, and comparing this information with the accounts of what went on prior to the onset of their stroke. That is, I am attempting to examine stroke recovery by examining the logic-in-use of stroke survivors. When specific categories of logic-in-use are discovered, it is indeed these categories, these forms of tacit knowledge that can be generalized beyond my specific sample. Tacit knowledge, or background expectancies, provides the working framework utilized in explaining how a given social world is structured. This underlying structure to the world of stroke recovery is brought to the surface by members’ accounts of what exactly it is that is going on with them and those around them.

**Reflexivity and the Research Design**

Thus far in the current section I have structured the discussion in such a way that it seems as though I am attempting to validate my interpretive approach. That is, by discussing the notion that there exists tacit knowledge, or background expectancies that
guide human behavior it may be said that I am attempting to scientize my work (Fontana and Frey 1994); I am using methods of validation borrowed from positivism (generality, sufficient sample size) in attempting to persuade the reader that my methodology is appropriate and rigorous. Rather than a conversation among paradigms as suggested by Guba and Lincoln (1994), Lyotard (1984) called for the annihilation of grand-paradigmatic strategies. This seems close to what Jacques Derrida (1976) did in defining all things as text and then promptly deconstructing the text, including his own text regarding another text. Basically, regardless of how hard one tries, no methodological stance is beyond critique.

Referring back to the discussion of Max Weber and the understanding of lived experience, there is always a selectivity of facts in scientific investigation. Indeed I have made factual selections at various stages of the analysis process. I chose the 31 participants whose transcripts have been transcribed for the larger multi-site study up to the point of me writing the current sentence. Also, with my theoretical orientation that suggests everyday life is always more complex than its representation through scaling instruments, I have set up a straw dog to illustrate this point (FIM; FAI). In essence I have been intimately constructing my data from the time I selected a research topic.

Adopting a theoretical perspective similar to that of Dorothy Smith (1987), the lived experience I have been talking about becomes problematic. Smith (p. 91) defined the concept of problematic as helping the sociologist relate to the experience of social members “as knowers located in actual lived situations in a new way.” The everyday world is seen as a place where questions originate, that is, as a social actuality that discloses and explains its own properties. This everyday world is itself organized by the
processes of social relations. It would be a methodological oversight to not at least acknowledge the participant-researcher relations from which data used for this dissertation were generated.

The qualitative interviews were structured (primarily by Dr. Maude Rittman), containing certain topics of interest designed to guide the conversation the data collector had with the stroke survivor. However, due to the fact that various personnel were interviewing at several sites throughout the state, the interview topics were broken down into specific questions the qualitative research team generally wanted answered. This more detailed structuring helped in maintaining continuity in measurement from interview to interview regardless of who the data collector was, but on the other side of the coin it likely also served to aid in the construction of the stroke subject. Sticking to the more specific research schedule provided greater reliability between interviews, but with a researcher going to the homes of the participants asking them a battery of questions related to stroke, stroke recovery was brought to the fore in the participant’s life, at least while we (the data collectors) were there. The nature of the qualitative interview leads to the technical issue regarding the world I am analyzing. More specifically, is the world I am analyzing the world of stroke recovery or the world of social scientific interviewing and the responses generally provided during such interviewing, which may or may not be relevant outside of this specific interactional context? Through conducting qualitative interviews, am I really getting at the stroke survivor’s lived experience, or am I getting at the experience of a given respondent answering specific questions in an interview setting? This technical dilemma is addressed further in the next section.
Issues in Interviewing

In his discussion of interviewing techniques Cicourel (1964, p.80) noted that the level of attractiveness or unattractiveness between researcher and participant, each other’s bodily presence in the environment, as well as the social, physical and role distance between them are all factors that “produce bias and error naturally because these are basic to the structure of everyday conduct.” Presenting the same interview schedule to all the participants in a study does not ensure standardization of the qualitative measuring instrument because social interaction and interpretation of communicative acts are altered with the introduction of new interactants into the interview situation. This means that there exist situational variables that create a uniqueness to all social events, even events such as qualitative interviews where the interviewer has been trained and a standardized interview schedule established. The focal concept here, as discussed by Cicourel (1964), is that of meaning structures. Meaning structures become anchored in the situation, shaped by various cultural definitions and differentiations actively used by the respondent and interviewer in the current meaning construction. This suggests that the interview itself is a (p. 103) “time object subject to moment-by-moment interpretations and redefinition.”

In acknowledging the multiple standpoints a respondent may take and the possibility that new meaning structures, not prepared for by the interviewer, may emerge during the interview, qualitative researchers agree with Harold Garfinkel (1967) that reality is an artful, ongoing accomplishment. More recently, Andrea Fontana (2002), John Johnson (2002) and Carol Warren (2002) address technical issues in conducting interview research. Warren makes a distinction between qualitative interviewing and survey interviewing. In qualitative interviewing participants are viewed more as
meaning-makers instead of a vessel of answers. Rather than attempting to discover social facts in respondent answers, qualitative interviewers see interviewing techniques as a way to collect and analyze interpretations of experiences. Experiences are discovered through open-ended questioning with the research questions remaining flexible enough to enable a variety of meaning structures to emerge during the interview. This flexibility, however, often implemented in the form of probes, also impacts the standardization of interviews. If each interview is more a narrative collaboration (Holstein and Gubrium 1995) than an extraction of already-made answers, it becomes difficult to assume the interview schedule represents a standardized measurement across interviews. The interview then becomes an active construction, a reality in and of itself, where the knowledge generated is situationally produced by interviewer and respondent Warren (p. 85) noted that qualitative interviewing techniques are often implemented instead of ethnographic methods when the topic of interest does not center on a particular setting but rather with “establishing common patterns or themes between particular types of respondents.” Referring back to the earlier review of Weber and Schutz at the conclusion of Chapter 1, the object of sociological inquiry should be formulating pure types of subjective meaning that are as close to the actual meanings experienced by the group under investigation. Where Weber discusses pure types, Schutz uses the term typification (stock of knowledge). That is, we typify our worlds in order to provide a meaningful structure to lived experience. One way of obtaining general typifications that are as close to lived experience as possible is through recording and analyzing social members’ reflections regarding their everyday worlds. Analysis of interview material becomes a method designed to bring out the themes that structure
one’s meaningful interpretation of their everyday experiences. Thus, in regards to the current research project there are two major systems of typification of stroke recovery: there are the clinical typifications generated by functional assessment and activities of daily living indexes, and there are the typifications generated by survivor reflections on the lived experience of stroke recovery.

Chapters 4 through 9 of this dissertation will be a presentation of these various typifications: (Chapter 4 analyzes FIM and FAI sample data, Chapter 5 provides an analysis of qualitative interview data as it relates to nourishing the self through eating and medication maintenance, Chapter 6 details how corporeality is negotiated when performing bathroom and dressing work as well as transference and mobility tasks, Chapter 7 addresses the issue of how shifts in locomotive activity can alter self-meanings, Chapter 8 presents an analysis of routine activities such as meal preparation and television viewing, as well as out of the home activities like bingo, swimming, boating, golf, Karaoke, golf, and motorcycle riding, and Chapter 9 offers a comparison regarding how clinical measures assess functional ability in comparison to how stroke survivors themselves reflect upon the topic). Chapter 9 also offers concluding remarks regarding the scientific value of the current research, summarizing the key points of the dissertation and suggesting future research possibilities.

In using qualitative interviewing as a means to get at the lived experiences of stroke survivors, such interviews necessarily become in-depth, asking myriad questions related to everyday routines, interpersonal experiences with family, friends, and strangers, as well as meaningful interpretations of one’s own embodied self in relation to the various interpersonal life-worlds respondents express as having bearing upon their day-to-day
lives. In order for a respondent to openly share such information, a degree of trust must be developed and cultivated (Johnson 2002). This enables the interview to unfold more easily as a collaborative partnership rather than simply a question and answer session. With various data collectors at multiple sites in the project, the current interview material creates a spectrum ranging from a high degree of interviewer-respondent collaboration in constructing a stroke recovery narrative to more unidirectional accounts that rigidly follow the questions on the interview schedule. While interviewers were matched with respondent in terms of race (white, African-American, Hispanic), many of the interviewers were female while the respondents were male. Further, oftentimes there was a generational discrepancy between interviewer and respondent. Such demographic differences may have limited the development and cultivation of trust between interviewer and respondent, particularly when dealing with sensitive issues such as sexuality and social embarrassment related to physical impairment.

Some respondents, whatever the reasons may be, are simply better than others in terms of the quality of the interviews provided. Quality in this sense is used to describe the richness or thickness of the accounts provided by the respondent. Some accounts provide thick descriptions of the stroke recovery experience. Others provide thick descriptions of experiences not directly related to stroke recovery. There are also respondents that provide thin, short accounts that provide little insight into stroke recovery or anything else for that matter. However, just because answers are terse does not necessarily mean they are void of theoretical and practical relevance. The illustrations provided in the chapters that follow represent various styles of respondent
description and hopefully aid in creating a thorough understanding of the life-world of high-functioning stroke survivors.

Earlier in this chapter I mentioned the influence French theorists J.F. Lyotard and Jacques Derrida have had on how social scientists come to view the search for truth. This influence, often defined as postmodernism, or a postmodern turn (Best and Kellner 1991), is frequently addressed as a crisis in representation where single representations become fragmented and ambiguity embraced. Fontana (2002, p. 162) commented that this postmodern turn shifts attention towards “minute fragments of everyday life, seeking to understand them in their own right rather than gloss over differences and patch them together into paradigmatic wholes.” Gubrium and Holstein (1998) suggested that lived experience is conveyed through stories. The interview is a narrative activity that makes one’s account organized and coherent. This way of conceptualizing the interview can be rooted in the classic paper written by C. Wright Mills (1940: p. 907):

When an agent vocalizes or imputes motives, he is not trying to describe his experienced social action. He is not merely stating “reasons.” He is influencing others-and himself. Often he is finding new “reasons” which will mediate action. Thus, we need not treat an action as discrepant from “its” verbalization, for in many cases, the verbalization is a new act. In such cases, there is not a discrepancy between an act and “its” verbalization, but a difference between two disparate actions, motor-social and verbal.

The stable world expressed during the qualitative interview does not exist a priori to the interview, but is rather constructed through the accounting practices of the respondent, which are in turn mediated by the interviewer’s structured questions, additional verbal probes, and non-verbal responses to the respondent’s communicative actions. This discussion regarding the active nature of reality construction is important for although interview material for this project is analyzed with the aid of a computer
software package, treating responses as cues into the everyday lives stroke survivors experience outside of the interview context, the current analysis does not ignore the negotiated nature of face-to-face narratives. Such negotiations are considered during the research stages of analyzing and presenting respondents’ accounts of living after stroke.

**Data Collection and Analysis**

To summarize: FIM and FAI scores have been compared and contrasted with coded semi-structured interviews that were conducted in the participant’s home at one month after discharge, logically recognizing how stroke survivors are dealing with everyday functioning. The interviews averaged around one hour and twenty minutes in length. Data was collected by a wide variety (current author included) of paid researchers at each VA site. Discharge data was collected in the hospital whenever possible, with one month data collected at the participant’s home unless otherwise requested by the participant.

Qualitative research team members coded using the computer software package NUD*IST. For the current project I created a specific subset of codes in NUD*IST linking items included in the FIM and FAI to specific aspects of physical functioning (e.g. walking) and activities of daily living (e.g. meal preparation) as they were expressed in the actual accounts provided by the respondents during the qualitative interview one month after their hospital discharge. The coding themes included as part of this analysis outside of the specific FIM and FAI subset deal with functioning time, health status, health symptoms, and mind/body talk.

These additional themes, generated by the qualitative research team, deal with body functioning in ways not specifically captured by the FIM and FAI. The primary outcome being examined in this dissertation is functional independence. The FIM and FAI data are used to represent the clinical meaning of stroke recovery and functional ability, with the
acknowledgement that these are but two measures out of many that clinicians may use in assessing recovery after stroke. The qualitative interview data, in describing their everyday lived experience, represents the practical understanding of stroke survivors regarding recovery and functional ability after stroke. Using the scoring definitions of the measure (outlined in chapter 1 of this dissertation), a high score (>107) on the FIM indicates that the stroke survivor has achieved the outcome of high functional independence, and a score that falls between 107 and 91 represents moderate independence.

The FAI, on the other hand, provides data regarding the frequency stroke survivors perform certain everyday activities, such as taking a bus, reading a book, or outside gardening. In attempting to understand the meanings to stroke survival expressed by those who retain or regain high functionality and return home, this dissertation research takes such outcome data (FIM, FAI) and compares it with personal accounts of functional ability and everyday activities (qualitative interview data). More specifically, coding categories generated from the qualitative interview will be compared to specific items on the FIM and FAI. Doing so requires that the stroke recovery process be understood as action-in-practice, using a comparative case study design in generating the relevant data.
CHAPTER 4
CATEGORIZATION MODELS FOR FIM AND FAI

The FIM and FAI were discussed in Chapter 1. The FIM is designed as a self-care measure that is rated by clinical personnel who have received training in rating certain functional activities as eating, dressing, walking, as well as cognitive ability as it relates to communication and comprehension. The FAI, designed to describe differences in lifestyle before and after stroke, is a measurement scale that attempts to distinguish groups of stroke survivors in terms of domestic, leisure and work, and social activities that go beyond those activities contained in the FIM. The FAI therefore, is practically relevant for stroke survivors who rate high on the FIM. In assessing stroke survivors rated as highly independent on the FIM, I am essentially examining what is commonly referred to as the ceiling effect. The ceiling effect of the FIM illustrates the failure of the measure to distinguish among the functional abilities of certain groups of stroke survivors, particularly those who can, to a high degree, perform the basic tasks the FIM examines. That is, where this group of stroke survivors may be treated as a homogenous group by the FIM, the FAI may treat the participants as heterogeneous in one or more of the activity categories the measure is designed to capture.

In this chapter I present various tables, highlighting the FIM and FAI scores for each case that is included in the sample. The personal factors for the sample are provided in Table 4-1. The variables contained in the FIM, FAI and demographic questionnaire
are taken into consideration in the following chapters in which participant constructions of stroke survival are outlined.

Table 4-1. Personal factors

<table>
<thead>
<tr>
<th>Case</th>
<th>Age</th>
<th>Race</th>
<th>Education</th>
<th>Marital status</th>
<th>Income</th>
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<td>1</td>
<td>2</td>
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<tr>
<td>4</td>
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<td>69</td>
<td>Hispanic</td>
<td>4</td>
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</tr>
</tbody>
</table>

Table 4-1 provides the age, race, education level, marital status, and income category for each case included in the dissertation. Age is provided in terms of number of years lived. The youngest participant is age 40; the oldest age 84. The mean age for the sample is 63.68 years, with a standard deviation = 11.28. The median age is 64, with multiple modes (3 cases = 51 years old; 3 cases = 57 years old). There are 2 participants
in their 40’s, 11 participants in their 50s, 9 participants in their 60s, 6 in their 70s, and 3 participants aged 80 or above. Race is provided as non-Hispanic white, African-American, or Puerto Rican-Hispanic. This sample consists of 16 non-Hispanic whites, 5 Puerto-Rican Hispanics, and 10 African Americans. Education level is broken down into the following seven categories

- 1 = less than 7 years
- 2 = junior high school: grades 7 to 9
- 3 = some high school: grades 10 to 11
- 4 = high school graduate
- 5 = some college or technical school
- 6 = college graduate
- 7 = graduate school: master’s degree or beyond

In this sample, 3 participants reported attending some high school; 9 participants reported graduating high school; 12 attended technical school or completed some college; 6 are college graduates; and 1 participant received a master’s degree or beyond. Twenty-two of the participants are currently married, 3 are widowers, and 6 are divorced. Total annual income is grouped into 5 categories. These categories are 1 = < $15,000; 2 = $15,000 - $25,000; 3 = $25,001 - $35,000; 4 = $35,001 - $45,000; 5 = > $45,000.

Thirteen of the participants reported earning less than $15,000 per annum, with 7 participants having an annual income ranging between $15,000 and $25,000. Five participants reported an annual income between $25,001 and 35,000, with 3 reporting earning between $35,001 and $45,000. One participant reported a total annual income greater than $45,000, with two participants declining to answer the annual income item.

Functional Assessment

With the primary personal factors outlined for each case in Table 4-1, Tables 4-2, 4-3, 4-4, 4-5, 4-6, and 4-7 present an extensive outline of physical functioning. The aggregate FIM scores for each case included in the sample are provided in Table 4-2.
These aggregate scores consist of the motor subtotal at discharge and one month after discharge, the cognitive subtotal at discharge and one month after discharge, and the overall total score (sum of motor and cognitive subtotals) at discharge and one month after discharge. FIM scores were rated using information provided by each respective participant. That is, the researcher went item by item asking the participant the amount of assistance, if any, the participant requires in order to successfully complete the functional task in question. Individual FIM items are outlined in the first chapter of this dissertation, along with an explanation of scoring procedures.

Out of the 31 cases, 17 indicated improvement in raw functioning, 11 indicated a decrease in raw functioning, with three participants scoring the same on the FIM at discharge and one month after discharge. If we follow the Stineman et al. (1995) FIM categorization models (see Table 1-1 of this dissertation), which focus solely on the motor subscores, the categorization models for the sample would be as displayed in Table 4-3. In Table 4-3 functioning is assessed at discharge with functional change through time measured by subtracting the discharge FIM motor subscore from the FIM motor subscore at one month after discharge. At discharge 28 of 31 participants fall in the high functioning range (Motor subscore = 65 to 91), with the remaining three cases falling into the moderate functioning category (Motor subscore = 56 to 64).

Having participants that are high in level of functioning at discharge is expected, considering that all but one (case 14; age 82, widowed, annual income less than $15,000, living in assisted living facility) was living at home one month after discharge. Those who are low functioning at discharge are much more likely to be discharged to a nursing
home or other long-term care facility. From Table 4-3, it would seem that two major categories can be defined for analysis

- High functioning stroke survivors who improve over their first month home
- High functioning stroke survivors who decrease in functioning over their first month home.

Table 4-2. Scores for FIM

<table>
<thead>
<tr>
<th>Cases</th>
<th>Motor D/C</th>
<th>Cog D/C</th>
<th>Total D/C</th>
<th>Motor 1mo</th>
<th>Cog 1 mo</th>
<th>Total 1 mo</th>
<th>Change</th>
</tr>
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<tbody>
<tr>
<td>1</td>
<td>88</td>
<td>35</td>
<td>123</td>
<td>91</td>
<td>35</td>
<td>126</td>
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</tr>
<tr>
<td>2</td>
<td>63</td>
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<td>94</td>
<td>71</td>
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<td>104</td>
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<td>3</td>
<td>82</td>
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<td>-45</td>
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<td>35</td>
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<td>125</td>
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<td>84</td>
<td>86</td>
<td>35</td>
<td>121</td>
<td>37</td>
</tr>
</tbody>
</table>

One may notice, however, that where the difference between the lowest possible score and the highest possible score in the moderate functioning category is 8, the difference between the lowest possible score and the highest possible score in the high
functioning category is 26. This indicates that those stroke survivors who are categorized as high functioning consist of a much broader range of functional assessment scores than those categorized as moderate functioning.

Table 4-3. Motor-FIM assessment of sample for first month after discharge

<table>
<thead>
<tr>
<th>Functioning</th>
<th>Low</th>
<th>Moderate</th>
<th>High</th>
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<tbody>
<tr>
<td>Motor-FIM score</td>
<td>N/A</td>
<td>Cases 2, 31</td>
<td>Cases 1, 3, 4, 12, 14, 16, 17, 19, 20, 22, 23, 24, 25, 27, 28, 30</td>
</tr>
<tr>
<td>improvement</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>through time</td>
<td>N/A</td>
<td>N/A</td>
<td>Cases 5, 11, 15</td>
</tr>
<tr>
<td>No improvement</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>through time</td>
<td>N/A</td>
<td>Case 18</td>
<td>Cases 6, 7, 8, 9, 10, 13, 21, 26, 29</td>
</tr>
<tr>
<td>Decrease in</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>motor-FIM score</td>
<td>N/A</td>
<td></td>
<td></td>
</tr>
<tr>
<td>improvement</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>through time</td>
<td>N/A</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Referring back to the outline of FIM items and scoring definitions, a score of 5 indicates that the person is able to perform the functional activity in question with supervision and less than 10% assistance, a score of 6 indicates that the person can perform the functional activity without supervision when aided by an assistive device or medication, and a score of 7 indicates that the person can independently perform the functional activity in a safe and timely manner. With a total of 13 items included in the motor subscore, a mean of 5.0 per item results in an overall score of 65. This means that those survivors that are aggregated into the high functioning category have an average score per item that indicates less than 10% assistance is required in performing the functional tasks. Those survivors aggregated into the moderate category have a mean per item score that is above 4 (actually above 4.3, but decimals are not used in the rating procedure) and below 5, indicating that on average, minimal assistance (10-25%) is required per functional motor task. Analyzing the categorization procedures in this
manner illustrates the fact that greater variation in functional experiences exists within the high functioning category in comparison to those that fall into the moderate functioning group.

That is, those who are high functioning may still require a large degree of supervision and/or a minimal amount of assistance in performing such tasks as dressing, eating, and walking, or they may be completely independent in performing the tasks specified on the FIM. Those that fall into the moderate functioning category require, on average, between 10-25% assistance per functional task. However, even in the moderately functioning category there may be variation from case to case regarding the specific tasks a given survivor requires assistance with. Such variation in scores for specific tasks is taken up later in this chapter.

The categorization models that follow Stineman et al. (1995) are not the only models that can be implemented in assessing functional ability post-stroke. In Chapter 1 I presented a categorization scheme following the scoring definitions outlined by the FIM that takes into consideration the overall total FIM score. This means that the cognitive subset is also included in such a categorization schemata. Recall from Chapter 1 that when using the FIM rating definitions it is possible to distinguish five distinct categories

- Highly dependent: FIM score ranging from 18-36
- Moderately dependent: FIM score ranging from 37-53
- Modified dependent: FIM score ranging from 54-90
- Moderately independent: FIM score ranging from 91-107
- Highly independent: FIM score ranging from 108-126
Table 4-4 illustrates the categorization model that may be utilized in describing the level of functional independence of the research sample if total FIM score is used rather than the motor subscore.

Table 4-4. Overall FIM score for first month after discharge

<table>
<thead>
<tr>
<th></th>
<th>Completely dependent</th>
<th>Moderately dependent</th>
<th>Modified dependent</th>
<th>Moderately independent</th>
<th>Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total FIM score</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>improvement through time</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>No improvement through time</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Decrease in total FIM score through time</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>

In Table 4-4 functioning is assessed at discharge using the overall FIM score. Functional change through time is measured by subtracting the discharge total FIM score from the total FIM score at one month after discharge. By doing so it is observed that 6 of the 31 cases were moderately independent at discharge and increased in functional assessment through time; 4 of the 31 cases were moderately independent and decreased in functional assessment through time; 11 of the 31 cases were highly independent at discharge and increased in functional assessment through time; 3 of the 31 cases were highly independent at discharge and indicated no change in overall score through time; and the remaining 7 cases were highly independent at discharge and decreased in functional assessment through time. Table 4-3 contains two categories in which the vast majority of participants fall into (high functioning, improvement; high functioning, decrease). Table 4-4 is not as distinct. One reason for this is that there is not as much range discrepancy between distinct categories. The category of moderately independent
has a FIM scoring range of 91-107, indicating a range of 16 between the lowest possible score and the highest possible score for that category. The category of highly independent has a FIM scoring range of 108-126, indicating a range of 18 between the lowest possible score and the highest possible score for that category. When compared to the range differences between moderate functioning (a difference of 8 between lowest possible and highest possible scores for the category) and high functioning (a difference of 26 between lowest possible and highest possible scores for the category) it is possible to see why more cases would fall into the moderately independent category in Table 4-4 (n = 10) than the moderate functioning category in Table 4-3 (n = 3).

The categorization model in Table 4-4 also shifts terminology from low, moderate and high functioning to that of modified, moderate, and high dependence/independence. Andrew Halpern and Marcus Fuhrer (1984) defined functioning as purposeful behavior in interaction with the environment. Margaret Nosek and Fuhrer (1992) described independence as being defined by control or self-direction. Each person must determine independence in terms that are meaningful to him or her. The FIM, through the clinical rating of various physical and cognitive tasks that links physical functioning with independence, seems to treat its specified meaningful activities as universal in their importance to the everyday lives of stroke survivors. Nosek and Fuhrer add that there are separate measurement instruments for the psychological, social, behavioral, and functional elements associated in the assessment of independent living. This indicates the lack of a comprehensive, operational definition of the central concept of independence. Although people may be rated as highly functional in all or most of the
items included on the FIM, they may still be dependent in certain aspects of their daily lives, and may not be capable of accomplishing specific personal functional goals.

Before analyzing participant’s expressed functional concerns however, Tables 6, 7, and 8 are presented below, illustrating the mean, standard deviation, and percent of sample that received a rated score under 6 for a given item. Table 4-5 provides data one month after discharge on the first six motor FIM items, which make up the self-care component of the measurement.

Table 4-5. Self care 1 month after discharge

<table>
<thead>
<tr>
<th>FIM item</th>
<th>Eating</th>
<th>Grooming</th>
<th>Bathing</th>
<th>Dressing upper body</th>
<th>Dressing lower body</th>
<th>Toileting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>6.68</td>
<td>6.23</td>
<td>6.00</td>
<td>6.19</td>
<td>6.06</td>
<td>6.48</td>
</tr>
<tr>
<td>Std. deviation</td>
<td>0.871</td>
<td>1.407</td>
<td>1.673</td>
<td>1.642</td>
<td>1.731</td>
<td>1.525</td>
</tr>
<tr>
<td>Percent rated less than 6</td>
<td>12.9</td>
<td>22.6</td>
<td>25.8</td>
<td>19.4</td>
<td>22.6</td>
<td>9.7</td>
</tr>
</tbody>
</table>

Table 4-6 provides data one month after discharge on the remaining seven motor FIM items, which make up the sphincter control (bladder and bowel); transfers (items bed, chair, wheelchair, toilet, tub, and shower); and locomotion (waling, wheelchair and stairs) components of the measurement.

Table 4-6. Sphincter control, transfers, locomotion 1 month after discharge

<table>
<thead>
<tr>
<th>FIM item</th>
<th>Bladder</th>
<th>Bowel</th>
<th>Bed, chair transfer</th>
<th>Toilet transfer</th>
<th>Tub, shower transfer</th>
<th>Walk, Wheelchair</th>
<th>Stairs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Std. deviation</td>
<td>1.31</td>
<td>1.31</td>
<td>1.33</td>
<td>1.29</td>
<td>1.41</td>
<td>1.02</td>
<td>2.52</td>
</tr>
<tr>
<td>Percent rated less than 6</td>
<td>9.7</td>
<td>9.7</td>
<td>19.4</td>
<td>9.7</td>
<td>16.1</td>
<td>9.7</td>
<td>32.3</td>
</tr>
</tbody>
</table>

Table 4-6 provides data one month after discharge on the remaining seven motor FIM items, which make up the sphincter control (bladder and bowel); transfers (items bed, chair, wheelchair, toilet, tub, and shower); and locomotion (waling, wheelchair and stairs) components of the measurement.
Table 4-7 provides data one month after discharge on the five cognitive items contained in the FIM. The comprehension and expression items make up the communication component, with the final three items making up the social cognition component.

Table 4-7. Communication and social cognition

<table>
<thead>
<tr>
<th>FIM item</th>
<th>Comprehension</th>
<th>Expression</th>
<th>Social interaction</th>
<th>Problem solving</th>
<th>Memory</th>
</tr>
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<tbody>
<tr>
<td>Mean</td>
<td>6.61</td>
<td>6.65</td>
<td>6.87</td>
<td>6.74</td>
<td>6.42</td>
</tr>
<tr>
<td>Std. deviation</td>
<td>0.80</td>
<td>0.88</td>
<td>0.72</td>
<td>0.77</td>
<td>0.96</td>
</tr>
<tr>
<td>Percent rated less than 6</td>
<td>6.5</td>
<td>12.9</td>
<td>3.2</td>
<td>3.2</td>
<td>9.7</td>
</tr>
</tbody>
</table>

Breaking down the FIM item-by-item provides further support for categorizing the sample as high functioning, moderate-to-highly independent stroke survivors. At one month after discharge the only item that does not have a median of 7.0 is stairs mobility (median = 6.0). The lower 25% quartile for bathing contains cases that were rated 5 or below. The lower 25% quartile for stairs contains cases that were rated 1 or 2. The remaining 16 items that make up the FIM indicate lower 25% quartiles containing cases rated 6 or under, or 7 or under. Thus, for only two items, bathing and stairs mobility, were at least one quarter of the case sample rated to require supervision or assistance. Only one item, stairs mobility, has a mean less than 6.0 one-month after discharge (4.97), indicating walking stairs is the only function that, on average, the sample group requires supervision or assistance when performing. Utilizing the standard deviation and percent of sample rated less than 6 for a given item helps assess the amount of motor-functional and cognitive variation for the sample. From this it can be seen that the sample is highly cognitive, with slight variation in scores. Comparing Tables 4-5 and 4-6
with Table 4-7 one finds that there is somewhat more variation in scoring in the motor subset than in the cognitive subset of the FIM. This can be expected when considering that adequate expressive and language comprehension skills are required for sample inclusion. Table 4-8 provides frequencies of scores for the motor FIM items where over 19% of the sample population indicated requiring at least supervision when completing the given task.

Regarding the self-care items, two participants required moderate assistance and five required minimal assistance while grooming, six participants indicated requiring 10% or greater assistance while bathing and dressing their upper body, and seven participants indicated requiring 10% or greater assistance when dressing their lower body. Six participants indicated requiring physical assistance while transferring from a bed and/or chair. Seven participants indicated that they were completely dependent when attempting to walk up stairs, two others required maximal assistance, with one other participant indicating the need for minimal assistance while attempting stairs maneuverability.

Table 4-8. Case analysis for assisted tasks

<table>
<thead>
<tr>
<th>FIM item</th>
<th>Grooming</th>
<th>Bathing</th>
<th>Dressing upper body</th>
<th>Dressing lower body</th>
<th>Bed, chair transfer</th>
<th>Stairs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Score =1</td>
<td>N/A</td>
<td>Case 26</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>Cases 9, 10, 11, 16, 18, 25, 26 Cases 14, 21</td>
</tr>
<tr>
<td>Score =2</td>
<td>N/A</td>
<td>Case 18</td>
<td>Cases 10, 26</td>
<td>Cases 10, 26</td>
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<tr>
<td>Score =3</td>
<td>Cases 18, 26</td>
<td>Case 21</td>
<td>Cases 18, 21</td>
<td>Cases 11, 18, 21</td>
<td>Cases 21, 26</td>
<td>N/A</td>
</tr>
<tr>
<td>Score =4</td>
<td>Cases 2, 10, 11, 13</td>
<td>Cases 9, 10, 13</td>
<td>Cases 11, 13</td>
<td>Cases 2, 13</td>
<td>Cases 2, 10, 13, 18</td>
<td>Case 2</td>
</tr>
<tr>
<td>Score =5</td>
<td>N/A</td>
<td>Cases 2, 19</td>
<td>N/A</td>
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<tr>
<td>Score =6</td>
<td>1 case</td>
<td>3 cases</td>
<td>1 case</td>
<td>1 case</td>
<td>5 cases</td>
<td>8 cases</td>
</tr>
<tr>
<td>Score =7</td>
<td>23 cases</td>
<td>20 cases</td>
<td>24 cases</td>
<td>23 cases</td>
<td>20 cases</td>
<td>13 cases</td>
</tr>
</tbody>
</table>
This analysis provides further evidence regarding the high rate of independence the stroke survivors included in this sample possess, at least when the activities measured are those contained in the FIM. The FIM results at one month after discharge indicate that approximately 4 out of 5 respondents are highly functional in all aspects measured with the following exceptions: case 9 indicated requiring minimal assistance with bathing, and total assistance with stairs; case 14 required total assistance with stairs; case 16 required total assistance with stairs; case 19 required supervision while bathing; case 25 required total assistance with stairs. Other than these noted exceptions there appears to be few middle-rated (5 or a 6) item scores, again indicating two clear groups of cases. The major case category contains the 24 cases making up high functioning, highly independent stroke survivors.

The remaining 7 respondents (cases 2, 10, 11, 13, 18, 21, and 26) require at least some physical assistance in various self-care and mobility tasks. Case two requires minimal assistance in grooming, dressing lower body, bed and chair transfer, and stairs and required supervision in bathing; case 10 requires minimal assistance in grooming, bathing, and bed and chair transfer, maximal assistance in dressing upper and lower body, and total assistance with stairs; case 11 requires minimal assistance in grooming and dressing upper body, moderate assistance in dressing lower body, and total assistance with stairs; case 13 requires minimal assistance with grooming, bathing, dressing upper and lower body, and bed and chair transfer; case 18 requires moderate assistance with grooming and dressing upper and lower body, maximal assistance with bathing, and total assistance with stairs.
These two groups of respondents will be implemented in orienting the initial analysis of functional assessment using the qualitative interview data; the largest group described as highly independent according to the FIM analysis makes up approximately 4/5ths of the sample population. The second group of participants, described as moderately independent according to the FIM analysis, includes the remaining 7 cases. The categorization procedure resulting from Tables 4-5, 4-6, 4-7, and 4-8 closely simulates the one proposed in the aggregate FIM score analysis illustrated in Table 4-4. One noted difference, however, is that case 13, which is included in the moderately independent category had an overall FIM score of 108 at one month after discharge, while case 25, included in the highly independent category had an overall FIM score of 105 at one month after discharge. The reason for categorizing these cases in such a manner stems from the analysis of Table 4-8, where case 13 indicates requiring assistance in a variety of motor-functional tasks, while case 25 is not able to walk up stairs. Case 25 also indicates some eating and sphincter control difficulties (rated a 5 for eating, bladder and bowel control). Cases 2 and 8 also follow a similar pattern. Although case 2, categorized as moderately independent had an overall score of 104 and case 8 categorized as highly independent had an overall FIM score of 109, case 8 requires assistance in bladder and bowel management, and also has comprehension, expression and memory difficulties. Thus, in actuality, where these cases fall in terms of level of independence is dependent upon what functional tasks are being evaluated more so that the overall score.

While stroke outcome research that utilizes FIM results commonly acknowledges variation in outcomes due to personal factors such as age, gender, native language, employment status, living situation, time lapse between stroke onset and hospital
admission, and discharge placement, previous studies that look at variation in outcomes as it relates to activities stroke survivors themselves express as meaningful in their day-to-day lives is rather limited. In other words, there is limited study of sub-samples of the stroke population commonly treated as homogenous by the FIM, such as high functioning stroke survivors who have returned home, analyzing patterns of meaningful recovery experiences from data expressed and narrated by the stroke survivors themselves. This is what I will do in the Chapters 5, 6, 7, and 8.

Stineman and Granger (1998 p. 201) noted that:

Once clinicians learn more about the determinants of functional recovery and the achievement of other types of outcomes and the mechanisms by which these outcomes occur, creative attempts may be undertaken to improve the process at multiple points in the treatment pathway.

Ultimately, the above statement by Stineman and Granger is the goal of this dissertation. That is, I have set out to learn more about the determinants of functional recovery and the achievement of other types of outcomes (dependence/independence in accomplishing personal life goals) and how they occur.

However, rather than clustering a national sample according to such variables as gender, employment status, marital status, age, living situation, and FIM score, I am attempting to learn more about the experiences of stroke rehabilitation through a detailed analysis of a sample that is generally treated as a homogenous cluster in comparison to other stroke survivors. In other words I am attempting to find the different meaning structures that exist in a population that is generally treated as possessing similar, if not the same meaning structures. This is accomplished primarily by setting previous research assumptions aside, allowing the stroke survivors themselves the opportunity to discuss the determinants of functional recovery and achievement of a specific outcome. In the
proceeding chapters I will utilize the break down of FIM items as illustrated in Table 4-8, linking qualitative data to the respective functional task, and presenting additional tasks described as important in the everyday lives of stroke survivors that are not captured by the FIM.

**Frenchay Activities Index**

Tables 4-9 and 4-10 describe the measurement scale that is designed to incorporate social survival into the assessment of stroke rehabilitation. The FAI was originally introduced by Margaret Holbrook and Clive Skilbeck (1983) specifically for measuring lifestyle activities of stroke survivors. Holbrook and Skilbeck state that the FAI is designed to measure activities beyond those related to self-care. The FAI contains items that are to reflect “the broader everyday activities of normal living,” (p. 166). Through factor analysis procedures Holbrook and Skilbeck recognize three main factors as part of the FAI. These factors are domestic chores, leisure/work, and a third, more ambiguous factor represented as outdoor activities. When asking 122 stroke survivors about their lifestyle prior to having the stroke (patients were asked within 6-weeks of the stroke event), female survivors scored higher on the first factor items related to domestic chores in comparison to male survivors (mean score = 7.0 and 4.1 respectively), with males scoring higher on items related to leisure/work (men’s mean = 6.3; females mean = 4.6). Males were noted to score marginally higher in outdoor activities as well (mean = 5.9 compared to a mean = 5.2 for females).

In comparing the pre-stroke activity mean scores with follow-up scores 12 months after the stroke event (obtained from a sub-sample of 39 patients), Holbrook and Skilbeck (1983) divided patients into stroke severity categories of mild and severe. Interestingly severity of stroke did not show a statistical significance for female scores, but did show a
difference in male domestic chore and outdoor item scores. It is concluded that a variety of items are sex-linked and therefore male and female scores should be treated separately. In relation to the current male-only study, it would be predicted that the sample would score low on items related to domestic chores (first 5 items) in comparison to items related to leisure/work and outdoor activities.

The FAI is discussed and outlined briefly in Chapter 1. To review, the first two items on the FAI, preparing main meals and washing up dishes, have four possible answers: 1 = never; 2 = under once weekly; 3 = 1-2 times per week; and 4 = most days. Items 3 through 10 on the FAI (washing clothes, light housework, heavy housework, local shopping, social occasions, walking outside for longer than 15 minutes, actively pursuing a hobby, and driving a car or taking a bus) have the following four possible answers: 1 = never; 2 = 1-2 times in 3 months; 3 = 3-12 times in 3 months; and 4 = at least weekly. Item 11, travel outings and organized car rides can be answered as 1 = never; 2 = 1-2 times in 6 months; 3 = 3-12 times in 6 months; and 4 = at least twice weekly. Gardening outside and household and car maintenance have the following rating procedure: 1 = never; 2 = light; 3 = moderate; and 4 = heavy. Reading full-length books is scored as 1 = none; 2 = 1 in 6 months; 3 = less than 1 in two weeks; and 4 = over 1 every 2 weeks. And gainful, paid work is scored as 1 = none; 2 = up to 10 hours per week; 3 = 10-30 hours per week; and 4 = over 30 hours per week. The FAI assessment for each case was conducted one month after discharge from the hospital, with the respondent asked to express his activity level since returning home from the hospital.

While not specified by Holbrook and Skilbeck (1983), it would appear that preparing meals, washing dishes and clothes, and light/heavy housework items would fall
into the domestic chore factor; social occasions, pursuing a hobby, travel, reading books
and employment would fall into the leisure/work factor; and local shopping, walking
outside, driving car/riding bus, gardening outside, and household/car maintenance would
fall into the outside activity factor, thus creating five items per factor. As presented in
Tables 4-9 and 4-10, sample FAI total scores range from 15 to 50.

Table 4-9. Scores for FAI items 1 – 8 (1 month after discharge)

<table>
<thead>
<tr>
<th>Cases</th>
<th>Meals</th>
<th>Dishes</th>
<th>Clothes</th>
<th>Tidying</th>
<th>Cleaning</th>
<th>Shopping</th>
<th>Occasions</th>
<th>Walks</th>
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</table>

A total score of 25 on the FAI represents the 25th percentile, a total score of 32
represents the 50th percentile (also referred to as the median) with a total score of 40 on
the FAI representing the 75th percentile. The sample mean score for the FAI is 32.35 with a standard deviation of 9.77. The mode is 32. The similarity in score among the mean, median and mode is representative of a normally distributed sample parameter.

Before suggesting sample categories regarding lifestyle activity, domestic, leisure/work, and outdoor activity scores are presented for each case. Table 4-11 presents sample totals for each of these three factors.

Table 4-10. Scores for FAI items 9 to 15 and overall score (1 month after discharge)

<table>
<thead>
<tr>
<th>Cases</th>
<th>Hobby</th>
<th>Car/Bus</th>
<th>Travel</th>
<th>Gardening</th>
<th>Maintenance</th>
<th>Reading</th>
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<td>3</td>
<td>36</td>
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</table>
Using the total FAI scores from Table 4-10 it is possible to create 3 categories of survivor lifestyles; minimally active (total score from 15 to 25), moderately active (total score from 26 to 39), and very active (total score of 40 or above). These categories are created utilizing the quartile scores for the sample that are discussed above. Doing so places 8 cases (25.8% of the sample) into the minimally active category, 15 cases (48.4% of the sample) into the moderately active category and 8 cases (25.8% of the sample) into the very active category.

Table 4-11. Total FAI scores for three factors (1 month after discharge)

<table>
<thead>
<tr>
<th>Cases</th>
<th>Domestic Chores</th>
<th>Leisure/Work</th>
<th>Outdoor Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
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<td>16</td>
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<td>29</td>
<td>17</td>
<td>16</td>
<td>17</td>
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<tr>
<td>30</td>
<td>10</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>31</td>
<td>5</td>
<td>18</td>
<td>13</td>
</tr>
<tr>
<td>Mean</td>
<td>9.71</td>
<td>11.13</td>
<td>11.52</td>
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</table>
However, if categories are organized according to the factor total scores presented in Table 4-11, the categorization procedure performed for the total FAI score is implemented for each of the three factors separately. For instance, for the factor of domestic chores, the 25th percentile indicates the minimum score of 5, the 50th percentile has a score of 7 or less, and the 75th percentile has a score of 16 or less. The mode for domestic chores is 5, with 12 respondents possessing this score. The next highest represented score is 17, with five respondents. In analyzing the quartile scores for each of the three factors described by Holbook and Skilbeck (1983) and extended in this chapter, the three categories outlined from the total FAI scores in Table 4-10 are represented as: minimally active (factor total score from 5 to 10), moderately active (factor total score from 11 to 14), and very active (factor total score of 15 or above). These categories are most evenly distributed in outdoor activities. Out of the total sample, 38.7% (n = 12) have a score less than 11, 32.3% (n = 10) have a score between and including 11 to 14, with the remaining 9 respondents (29% of the sample) having a score above 14. For leisure/work the percentages per category are: minimally active = 35.5% (n = 11) of the sample, moderately active = 45.1% (n = 14) of the sample, and very active = 19.4% (n = 6) of the sample.

In stating that the modal category for domestic chores = 5, with the next most represented score = 17, a difference between the domestic chore factor and the other two factors is illustrated. Namely, in relation to this sample of male stroke survivors there is little middle ground in the performance of domestic chores. Twenty of the 31 cases fall into the minimally active category for domestic chores. This represents 64.5% of the sample. Conversely, 32.3% (n = 10) of the sample falls into the very active category.
Only one respondent falls into the moderately active category, scoring a total of 11 for the domestic chore factor. Again, this analysis provides support to the conclusion that males are less likely to be active in domestic chores than in leisure/work and outdoor activities, but also points out two distinct groups of men; those that do housework and those who do not. For the other two factors, such a distinction in non-activity/activity is not as easy to demonstrate. It may be that living situation plays a part in distinguishing who falls into the minimally/very active domestic chore categories. Out of the 10 cases that make up the very active group, 3 out of the 4 sample cases who live alone are very active in domestic chores, two of who are divorces, with the third having a wife who lives in a nursing home. The other 7 cases that make up the very active in domestic chores group live with their specified caregiver. Thus, while living alone may be a factor in determining amount of domestic chores one must perform, it is not the sole factor.

With various categories generated from the separate analysis of FIM and FAI data, the next step is to attempt to create discreet categories of respondents through an analysis of the relationship between FIM and FAI scores. From analyzing the FIM results respondents were ultimately categorized as either moderately (cases 2, 10, 11, 13, 18, 21, and 26) or highly (the remaining 24 cases) independent. From analyzing the FAI results respondents were categorized as minimally, moderately, or very active. The cases categorized in a particular fashion are dependent upon whether the categorization procedure is utilizing the total FAI score or looking separately at the three factor subtotals. When utilizing the overall FAI score cases 1, 2, 9, 10, 11, 18, 25, and 26 are categorized as minimally active; cases 4, 8, 17, 22, 23, 28, 29, and 30 are categorized as highly active, with the remaining 15 cases categorized as moderately active. When
separating categorization models according to each of the three factors represented in the FAI, the analysis obviously becomes more complicated. These categorization models are illustrated in Table 4-13.

**Table 4-12. Analysis of FAI items (1 month after discharge)**

<table>
<thead>
<tr>
<th>FAI item</th>
<th>Mean Response</th>
<th>Cumulative percent</th>
<th>Response = 1</th>
<th>Response = 2</th>
<th>Response = 3</th>
<th>Response = 4</th>
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<td>18</td>
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<td>3</td>
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<td>22</td>
<td>71.0</td>
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<td>74.2</td>
<td>87.1</td>
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<tr>
<td>4</td>
<td>2.03</td>
<td>18</td>
<td>58.1</td>
<td>2</td>
<td>64.5</td>
<td>74.2</td>
</tr>
<tr>
<td>5</td>
<td>1.97</td>
<td>18</td>
<td>58.1</td>
<td>3</td>
<td>67.7</td>
<td>77.4</td>
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<td>4</td>
<td>51.6</td>
<td>74.2</td>
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<td>77.4</td>
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<td>26</td>
<td>83.9</td>
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<td>87.1</td>
<td>93.5</td>
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</tbody>
</table>

If we first compare the two major categories derived from the FIM data with the three categories derived from the FAI total score data, two groups to analyze for comparability are the moderately independent stroke survivors to those categorized as minimally active on the FAI, documenting the degree of overlap between these two categories. With the cases included in each of these categories discussed earlier in this chapter, one finds that cases 2, 10, 11, 18, and 26 are categorized as moderately independent, minimally active stroke survivors. Cases 13 and 21 are moderately independent, moderately active stroke survivors with case 13 at the 50th percentile in
terms of FAI score and case 21 scoring below the mean on the FAI one month after discharge (case 13 FAI total score = 32; case 21 total FAI score = 27). The remaining cases included in this comparison, cases 1, 9, and 25, are categorized as highly independent, minimally active stroke survivors. This eyeball analysis illustrates some positively directed relationship between the FIM and FAI ratings. Yet, even if one is independent in relation to self-care tasks (FIM), it may be that they are relatively inactive in other, more social tasks (FAI). That is, people may still have different lifestyles independent of their physical functioning.

Table 4-13. Categorization models for FAI factors

<table>
<thead>
<tr>
<th>Categorization</th>
<th>Domestic Chores</th>
<th>Leisure/Work</th>
<th>Outdoor Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimally Active</td>
<td>Cases 1, 2, 3, 5, 7, 9, 10, 11, 12, 13, 15, 16, 18, 20, 21, 24, 25, 26, 30, 31</td>
<td>Cases 1, 2, 4, 6, 9, 11, 18, 19, 25, 26, 27</td>
<td>Cases 2, 3, 10, 11, 14, 15, 18, 20, 21, 25, 26, 27</td>
</tr>
<tr>
<td>Moderately Active</td>
<td>Case 14</td>
<td>Cases 3, 5, 7, 8, 10, 12, 13, 14, 15, 21, 22, 23, 24, 28</td>
<td>Cases 1, 8, 9, 13, 16, 17, 19, 22, 23, 31</td>
</tr>
<tr>
<td>Very Active</td>
<td>Cases 4, 6, 8, 17, 19, 22, 23, 27, 28, 29</td>
<td>Cases 16, 17, 20, 29, 30, 31</td>
<td>Cases 4, 5, 6, 7, 12, 24, 28, 29, 30</td>
</tr>
</tbody>
</table>

There is a rather strong statistical relationship between FIM and FAI results one month after discharge. Of course analyzing this relationship through linear regression procedures can only serve certain purposes due to the nonprobabilistic nature of the sample data used for the analysis. While the statistical relationships should not be generalized to a larger population, they still have significance in illustrating the relationship between the two measures as they relate to this particular sample of male stroke survivors. In other words, the following statistics are not presented for the purpose of predicting relationships in some sort of hypothetical population, but rather to illustrate
the relationship between the FIM and FAI total scores for the specific population under study. This follows the current case analysis research design, which relates clinical measures (FIM and FAI) to the everyday functioning of stroke survivors at home and in public milieus. It is logical to believe that to a certain extent differences in physical functioning will relate in a linear fashion to differences in social activity level.

The specific prediction is that those cases who are rated lower in physical functioning on the FIM will tend to score lower (indicating lower social activity levels) on the FAI. This prediction is stated in the specific manner of decreased functioning to imply that the variation in FAI scoring associated with FIM rating is most prevalent for moderately functional, minimally to moderately independent stroke survivors. It is most logical to assume that stroke survivors who have trouble in the more ordinary self-care tasks on the FIM will be even more limited in the activities detailed in the FAI. Variation in lifestyle as opposed to the impact of functional limitation seems most likely to be realized among those who are highly independent in self-care tasks and therefore more likely to be able to perform additional social activities if so desired. In other words functionality has more impact in the social worlds of stroke survivors when physical functioning itself is a practical, everyday concern. That is, functionality has the most direct impact on a person’s lived experience when the body dys-appears.

A slope of .414 with a standard error = .085 is obtained when FIM total scores at one month after discharge are regressed on the total FAI scores. The t statistic is equal to 

\[
\frac{.414}{.085} = 4.87
\]

This shows a statistically significant positive relationship between FIM and FAI score, but since the t statistic is based upon simple random sampling, the statistical significance that is indicated cannot be related to the general population of
stroke survivors. Still, these statistics indicate a positive linear relationship between FIM and FAI score, and the data presented in this chapter indicate that both FIM and FAI scores fall on a normal distribution curve. The regression equation has a Pearson correlation of .67 with an $r^2 = .45$. The Pearson correlation is a standardized version of the slope that indicates the value of the slope when assuming equal standard deviations for the FIM and FAI variables. Since the FIM score has a range of 18-126, while the FAI has a range of 15-60 it is likely that the FIM will have a higher standard deviation than the FAI since it has a wider range of possible scores, and indeed this is the case for the sample parameter ($s$ for FAI = 9.77; $s$ for FIM = 15.79). Since $r$ standardizes this difference, it serves as a better indicator of the linear relationship of FIM and FAI score than does the unstandardized regression coefficient (slope), which does not take measurement units into account.

The Pearson correlation (.67) measures the strength of the linear association between FIM and FAI score at one month after hospital discharge. Unlike the slope, the Pearson correlation treats the variables symmetrically, meaning that an equation that uses FAI score to predict FIM score has the same correlation as the one that uses FIM score to predict FAI score. The coefficient of determination, or $r^2$, indicates the proportional reduction in error that results from using the linear prediction equation (FIM score regressed on FAI score) instead of the mean FAI score to predict FAI score. Figure 4-1 presents the simple scatterplot of the regression equation. Some of the points that can be visualized in Figure 4-1 are: the majority of scores fall at the high end of FIM score as discussed. It also shows a fairly strong linear relationship until FIM score reaches its highest range of 120-126. The scatterplot represents the relationship indicated in my
prediction that those who score lower on the FIM will tend to score lower on the FAI (dys-appearance of the body). The wide variety in FAI scores at the high end of FIM score also supports my suggestion that lifestyle choices become more of a concern for stroke survivors when one’s bodily functioning does not necessarily make everyday life problematic, at least for all practical purposes.

Figure 4-1. Scatterplot of FIM scores regressed on FAI total score (1 month)

The analysis in this chapter extracts information FIM and FAI scores provide researchers about this specific stroke survivor population. Social statistics can be used to investigate variable relationships within sample data and to generalize such relationships generated from a randomized sample to the larger, overall population. Due to the nature of the sampling technique, the generalization component of statistical inference is not appropriate for this study. However, when discussing the data related to the 31 cases included in the study, variable relationships such as the relationship between FIM and FAI scores can be analyzed. While the UDS and the vast majority of all the research that utilizes the FIM concentrate on large-scale generalizations and trend analysis, this dissertation approaches it from a different angle. That is, rather than starting from
research generalizations and moving to the more general description of an overall population, I have started at the general (FIM; FAI scale data) and will now move to the more specific (everyday lived experience of 31 stroke survivors), concluding with a general schemata of survivor categorizations based on a detailed analysis of topic-specific qualitative interviews that were conducted with the stroke survivors under study. As indicated by the FIM analysis, the general schemata formulated at the conclusion of this dissertation will have significance for moderately to highly independent male stroke survivors.

Two distinct groups of cases included in this study are distinguished through the use of FIM data, three distinct groups through the use of total FAI score data, and eight groups when using FAI factor totals. These groups, however, often overlap with the same case included in various categories. The general categories distinguished by these analyses are further analyzed through qualitative analysis. It may be that the boundaries that distinguish these groups disappear once the stroke survivors themselves discuss their everyday lived experiences; or it may be that the boundaries become generally reinforced. Furthermore, it may be that for all practical purposes the groups generated by the FIM and FAI analysis are fine for some of the cases, while other cases shift from one group to another dependent upon contingencies not yet taken into account by the clinical scaling instruments.

A strong linear relationship was noted between the FIM and FAI one month total scores, with a 45% reduction in error when using the linear regression model rather than simply the FAI mean score (32.35) to predict FAI scores. Also noted was that there is great variation in FAI score at the high end of FIM scores (scores of 120 and above).
These highly independent stroke survivors who are capable of self-care may have other practical concerns in comparison with stroke survivors requiring assistance in certain mundane tasks of everyday bodily functioning. Also, for highly independent stroke survivors, the types of environments they routinely enter and the specific activities expressed by them as important in everyday life will impact the level of concern they have regarding physical functioning. For some, the stroke may have little impact on their everyday routines. For others, the stroke may alter one’s lifestyle greatly. Qualitative data becomes particularly important for researchers concerned with the social aspects of stroke survival when the activities survivors express concern with are routines not specified on the FIM or FAI.

It’s recently been noted (Wasserman 2001) that most disability scholars agree limitations from physical impairment are produced from the interrelationships among biological, environmental, and personal goal-oriented factors. Referring back to the conceptual models presented towards the end of chapter 2, Granger’s (1984) model clearly delineates three major conditions: 1) Pathology, 2) Behavioral, and 3) Role Assignment. Pathology conditions represent biological factors (diagnosis), behavioral conditions represent goal achievement factors (task performance) and role assignment conditions represent environmental and social factors that are impacted by general attitudes and social policies, creating social disadvantages for people with certain physical impairments. The conditions illustrated by Granger (1984) are related respectively to impairment, disability and handicap. The directional arrows among these key terms indicate that each is interrelated to the others, thus disagreeing with the former unidirectional framework commonly referred to as the Nagi (1965) diagram.
Altman’s (2001) addition into the Nagi framework of role as defined by social interaction seems to differ from the way Granger (1984) discusses role assignment. Granger’s discussion of role assignment is extremely structural, seemingly eliminating individual agency through the use of such ambiguous terminology as social norms and societal deficits. That is, Granger does not seem to take into account the meaning-making processes involved in day-to-day social interaction and hence fails to recognize the semi-permeability of role assignments which take form within shifting contexts as well as variations in audience response. Altman discusses Nagi’s comments (1965, p. 103) regarding the definition of the situation, formed through the responses of others as the way by which personal roles become shaped via social interaction. Granger’s discussion of handicap looks at such situational definitions as being formed via social norms and policies. This by itself, however, actually tells us very little. What are the social norms and who gets to decide what these are? Do such norms apply universally in all situations across time for everyone?

Universally applying the concepts of social policies and social norms to explain the everyday lives of people is representative of a specific type of grand narrative. Certainly some grand narratives are more applicable to everyday life than others. For instance, if it is agreed by the participant and myself that we meet at a specific address in Sunshine County at 1pm on Tuesday June 4th we are taking for granted that each of us are oriented to a particular world where space can be mapped-out and events dissected according to a specific time-frame. In contemporary American life (Garfinkel 1967) such meaning structures of time and space usually go unchallenged (remain taken for granted). However, when discussing the concepts of disablement, handicap, and lifestyle, these
meaning structures are often results of face-to-face negotiation, with meanings shaped by interpersonal and environmental considerations. While people may not frequently negotiate the meaning of time, they often do negotiate the meaning of disability and/or handicap. Different people may discuss everyday goals and challenges in different ways depending on what practical considerations are taken into account in their lived experience. These differences in accounting practices get lost when research relies solely upon scaled measurement techniques, generalizing the results derived from these scales to the overall population (a population ultimately defined by mathematical theory).

Cicourel (1981 p. 65) agreed:

> Individual differences and their reflection of lived or daily-life group perspectives are never studied and reported independently of the survey itself. The aggregated responses provide their own collective reality by the choice of variables for creating classes or ‘groups’.

> By categorizing daily functioning through the analysis of stroke survivors’ own narratives, practical goals, and the challenges stroke survivors face in meeting these goals, are explored in extensive detail. This allows meaning structures to emerge that may not have been acknowledged by data structured according to research considerations rather than the practical everyday considerations of those being studied. Cicourel (1981 p. 65) added that it is in the study of everyday settings that the routine features of cultural and social organization are discovered. Such discovery entails an integration of micro- and macro-level analysis. In other words, the goals and challenges survivors express are not formed out of thin air. These expressed goals and challenges are culturally organized knowledge structures produced by the relationships between environmental factors and processes of social interaction. That is, everyday settings provide organized possibilities (macro-level analysis) that are continually worked with by those involved in the situation
(micro-level of analysis). To understand the functional realities of stroke survival is to understand both the organized possibilities presented to the survivors in the everyday settings they are located in as well as understanding how these possibilities are acted-out through the social interaction of survivors and those around them.

**Linking Quantitative with Qualitative Data**

Methodologic triangulation is fairly common in postpositivist research (Ford-Gilboe et al. 1995), but qualitative interviewing techniques are often seen as the initial step in the research process. When used as a preliminary method prior to large-scale quantitative analysis, or to provide new insights that can strengthen particular quantitative techniques, qualitative data becomes more of a tool that quantitative researchers can use to strengthen their numbers more than an integral component in the understanding of everyday life. This dissertation follows in the tradition of Aaron Cicourel in that it attempts to understand both the organized possibilities that exist for stroke survivors in everyday settings and how such possibilities are acted-out through social interaction. The macro-level, organized possibilities of social settings may be partly analyzed via quantitative measures, while the micro-level analysis of how people interpret these possibilities, artfully producing lived realities, generally requires interviewing and ethnographic methods.

Ford-Gilboe et al. (1995) noted that using particular quantitative measures as a method to refine and contextualize patterns that emerge from in-depth qualitative interviews does not compromise the quality of the research, but rather may help in providing new insights and extending concepts that emerge from the interview data. This style of data collection and analysis is one way to combine macro- and micro-level analysis with ontological assumptions that are grounded in the interpretive paradigm.
Certain research factors may exist in the environment, but it is up to those involved in the situation at-hand to acknowledge and use these factors. If the people under study do not acknowledge certain environmental factors, then for all practical purposes these factors are of little use in explaining everyday lived experience, even if a statistical relationship exists.

Treating certain environmental factors as meaningful in and of themselves in the everyday lives of the people being studied ignores the interpretive and negotiated nature of everyday life. Particular to disability studies, the work of Irving Zola (1982) detailed how the missing piece in medical sociology to understanding what it means to live with physical impairments is understanding the lived experience of living with a physical impairment as it is expressed by those who are actually physically impaired. Through the use of personal diary/narrative, Zola (1982) illustrated how the dominant knowledge structure of disability actually serves to limit the possibilities disabled people have in social environments. In essence, the acting out of a specific meaning structure is what is disabling, more so than the physical impairment itself. While this understanding of disablement is readily acknowledged in current literature, there still exits a dominant meaning structure, albeit altered (ICIDH-1 to the ICIDH-2), that is to be operationalized into measurable research variables and then generalized to the overall population who possess a specific health condition.

When dealing with stroke survival specifically, the principal goals for research are outlined in Figure 2-6 of this dissertation. Yet, as Duncan et al. (2000) stated, characterizing stroke recovery can be rather elusive. What is meant by recovery? Who decides what recovery means? Is getting back to normal a reference to motor
improvement in the impaired limb or to the survivor learning new ways of dealing with environmental situations as a means to compensate for motor loss? What’s the influence of specific rehabilitation techniques in stroke recovery? How does one control for rehabilitation techniques that may vary according to time, place, and interpersonal contingencies? The meaning to recovery can be seen as determined by assessing scores on motor and ADL scales such as the FIM and FAI, relating these scores to various environmental factors such as the receiving/non-receiving of specific rehabilitation techniques, race, age, gender, education, income, and living situation. If recovery is dealt with in such a manner, however, the factors influencing recovery as well as the meaning of recovery itself is determined by research considerations rather than by the considerations of the stroke survivors. Such practical, lived considerations of the stroke survivors may be highly correlative to the considerations of the researchers, or they may differ in significant ways.

In this dissertation, such factors as race, age, education, income, and living situation are taken into consideration (see Table 1-1 of this dissertation), and other factors such as gender (all males), presence of caregiver, and in-hospital rehabilitation treatment (all participants are discharged to home after hospitalization) are controlled for through inclusion criteria. While FIM and FAI data are available as a means to measure recovery status, in-depth qualitative interviews enable the researcher to form what recovery means in terms that are expressed as important to everyday life by the people being studied. Further, Duncan et al. (2000) noted the general failure in distinguishing heterogeneous stroke survivor groups. That is, in general the stroke literature treats all stroke survivors as going through a similar experience. Assessing stroke as minor, moderate, or severe
can be somewhat complicated. In analyzing the FIM data for the cases included in this study, one may conclude that at least most of the stroke events discussed may be categorized as minor when compared to all stroke events that have taken place during the same time-frame. However, such factors as co-morbidities, age, and current lifestyle will also likely influence how the stroke survivor determines the level of severity the stroke event has been on his everyday lived experiences. Again, there are measures that can control for these factors, but whether or not these measures have practical meaning to those being studied cannot be determined without analyzing how the stroke survivors themselves use and interpret these factors in specific everyday situations. That is, the practical research considerations regarding stroke recovery may not be completely congruent with the lived, everyday, considerations of stroke recovery.

Stroke assessment will be taken up as a specific topic of investigation in Chapter 8 of this dissertation. At this point, however, we have grouped cases into severity categories based on FIM rating at one month after discharge to their home. When measuring severity by loss of motor and/or cognitive functioning the major category included in this dissertation would be considered as having a minor stroke event. Twenty-four out of the thirty-one cases are rated as highly independent in self-care and cognitive areas, with the remaining seven cases rated as moderately independent. Chapters 5 and 6 present the expressed considerations of stroke survivors regarding physical functioning at home and in public respectively. Before presenting the lived experience of stroke survivors at home, however, presented below is an evaluation of the working conceptual framework of stroke recovery.
Meaning of stroke recovery

(Highly independent; moderately independent in self-care/motor/cognitive tasks)  (Minimal, moderate, very active lifestyle)

Use of assistive devices
support/assistance from others

Race, age, gender, income, education and marital status

Figure 4-2. Stroke recovery framework incorporating FIM and FAI data

In comparing the current representation of the stroke recovery framework to that of the initial representation of the framework in Figure 2-6, the most notable absence in the current representation is the influence of social interaction as it relates to the recovery process. While there is a social interaction item on the FIM, that provides little if any insight into how specific interactional contexts influence the interpretation of stroke recovery. Attempting to analyze such influences via scaling items trivializes the complexity of reality production and silences the voice of those being studied by limiting their possibilities to a set number of questions and answers. What is provided in the representation in Figure 4-2 are specific ways of understanding physical functioning and activities of daily living, with categories regarding functioning and activities formed for the population currently under study. At this point in the dissertation it is possible to take a given case and fill in the conceptual boxes illustrated in Figure 4-2 with specific descriptive answers. The meaning of stroke recovery, however, can go no further than the measurement instruments themselves allow.
An item-by-item comparison between the FIM and the qualitative interview material was accomplished by linking the coding of interview material to FIM items. The transcripts of the one month after discharge qualitative interviews for the 31 cases were imported into the computer software program NUD*IST and a coding category was created for each FIM item. Specific extracts from the transcripts were then coded to the related FIM item. The same analysis procedure was implemented for the FAI. While not all items included in the FIM and FAI are prominent in the survivor narratives, there are several self-care tasks, locomotive activities, and cognitive abilities such as speech and memory that do figure into the qualitative analysis. There are several items on the FAI that relate to functioning at home as well as in public. These items consist of domestic chores such as cooking, laundry and cleaning the house, home leisure activities such as watching television and gardening outside, household and car maintenance, as well as social outings and travel.

This chapter deals with how those who are understood to be relatively independent stroke survivors nourish their self during their first-month after hospital discharge through the practical everyday accomplishments of dietary regimen and medication maintenance. The phrase “nourish their self” is used to invoke the question of pleasure considered by Foucault (1986). While Foucault’s historical analysis primarily deals with issues of sexuality, the current chapter links medical knowledge with an authoritarian
raise of moral standards. Medical work often demands docile, obedient bodies. As I will show, stroke survivors who are categorized as similar bodies by the FIM and FAI often deal with everyday interpersonal and environmental situations in complex ways that differ from one another. While complex differences emerge from the extracts, distinct patterns also form. These patterns go beyond what the measurement analysis presented in chapter 4 offers social scientific investigators. Such patterns are reflected upon in communicative acts where stroke survivors invoke their tacit knowledge when meaningfully producing accounts of everyday life.

**Self-Care**

Eating, grooming, bathing, dressing, and toileting are activities labeled as self-care tasks by the FIM. All of these tasks consist of activities that are related specifically to body maintenance and physical presentation. However, while the FIM focuses on motor and cognitive functioning in measuring self-care, there are other aspects involved in self-care that stroke survivors express as being of primary concern in their everyday embodied experiences. That is, experiences where the body itself signifies one’s subjectivity. Holstein and Gubrium (p. 197 2000) defined embodiment as the centering of “the material body as a mediating feature of everyday life.” This corporeal centering in lived experience treats the body as a social project, with the sociological question becoming (p. 198): “How does the body as a primary material presence in life serve as surface for the narrative embodiment of subjectivity?” This will be used as the orienting question for the remaining components of the dissertation. Hopefully, through a view of the body in interpretive practice it becomes more apparent how the three primary research questions noted in the first paragraph in Chapter 3 will be answered, as well as
further clarifying what is intended when proposing to collapse the mind/body duality and
decenter corporeal knowledge.

There is the clinical self, which is viewed as an anatomical atlas that demarcates the
lines, volumes, and surfaces of the body in accordance to a medical knowledge that
becomes an invisible visibility. But the lived self (Holstein and Gubrium 2000) is often
oriented to the world by various stocks of knowledge, including but not exclusive to
medical discourse. Rather than an isolated mechanism, the self is a social structure that is
generated and regenerated through the practical accomplishments of everyday life. In
constructing their life through language, stroke survivors are actively participating in
meaning formation that is localized in the content of their talk. The qualitative
interviews, to an extent, enable the stroke survivors the opportunity to produce who and
what they are. This production may closely align with clinical understandings at times
(when the stock of knowledge being used to describe experience is embedded in medical
practice), while at other times it may radically differ (when the stock of knowledge used
to describe experience is not embedded in medical practice, but rather in some other form
of discourse). Stated another way, there may be, and commonly are, multiple discourses
implemented in everyday life. If acknowledging this, clinicians may then implement a
different scale, such as the FAI in trying to capture lifestyle, rather than raw functioning.
Criticisms of these scales are likely to be well-known by specialized clinicians within the
field, the expectation being that through time more efficient scales will be produced and
implemented.

While frequently acknowledging that aspects of meaning production such as
context and reflexivity exist, it is not uncommon for clinicians to express disinterest in
these aspects once they are brought to the fore. This is because for all practical purposes, that is, for the practical purposes of clinicians, such lived experiences are of little consequence to a self routinely treated as an anatomical atlas. As detailed by Foucault (1973) this is historically the work of the clinic. The clinic is a social space where bodies are worked upon; it is a space where bodies are treated as diseased spaces. Rather than understanding lived experience through the collection and analysis of everyday language, the main goal for clinicians is maximizing the efficiency of scaling instruments, which enables them to group and categorize certain types of diseased bodies. For those concerned with understanding life in various social contexts outside of the clinic, however, efficient scaling instruments may by themselves remain inefficient at capturing the meaning of the lived experience of stroke survivors; particularly those survivors whose practical concerns are not adequately captured by commonly used clinical measures.

**Eating**

The first FIM item, eating, provides an example of how traditional functional measurement may not assess certain factors related to self-care that those surviving from stroke assess on a daily basis. The FIM defines the task of eating as follows: “Includes use of suitable utensils to bring food to the mouth, chewing and swallowing, once the meal is appropriately prepared.” Functional independence in eating as defined by the FIM is simply having the ability to put food into one’s mouth, then chewing and swallowing the food. The only cases not to be rated as completely independent for the eating FIM item are cases 10 (moderately independent; eating score = 5), 11 (moderately independent; eating score = 4), 21 (moderately independent; eating score = 4), and 25 (highly independent; eating score = 5). This implies that 27 out of the 31 cases are able
to use eating utensils, chew, and swallow food without any assistance from a device or person, and that of the four survivors who do require some assistance in the physical process of bringing food to one’s mouth and digesting it, three are categorized as moderately independent stroke survivors in terms of overall FIM score.

The impact of utensil-holding difficulty was only addressed by one case, case 30, a married 74 year-old non-Hispanic white with some high school education and an annual income below $15,000. In his description of eating tasks, sometimes his wife cuts his meat and other times he does it himself. Rating when he does not require meat to be cut for him, case 30 rates a 7 on the FIM eating task. Rating at a time when he requires assistance in meat cutting, the score for the task changes from a 7 to either a 4 or a 5. However, as the following extract from case 30’s interview shows, the stoke survivor’s physical impairment causes little limitation while eating because he has learned new techniques that do not require the use of his impaired hand. Here and throughout, speakers appear in the interview transcripts as “participant” (par) for those interviewed and “interviewer” (int) for those doing the interviewing.

Par: Usually I get up and have breakfast first. (Chuckles) I'm always hungry. And uh, ah, in the morning anyhow. And it's typical, I mean everything is typical like it has been before the stroke even. Ah, 'cause it don't bother me that much at what I have lost in, in uh, the use of this hand, I make it up with my right hand. [a bit later in the interview]

Int: Could you see any problems that another veteran might run into with their family or friends after the stroke?

Par: Not unless he was uh, well uh, couldn't motivate his self, couldn't, couldn't do a thing for himself. He might have run into problems with people havin' to do everything for him. She was there all the time for me and if I needed my meat cut up she'd cut my meat or if I need uh, to do anything she done it for me. But when I do it myself then I done it myself.
Case 30 does not see a problem in surviving after stroke as long as one can motivate his self. This motivation is illustrated by his adapting to living with an impaired left hand by compensating with his right hand. Prior to learning the necessary compensation techniques his wife was there to assist him. Now, “when I do it myself then I done it myself.” Following from the review of research literature, it can be concluded that sometimes improved physical functioning after stroke is not due to physical rehabilitation of the impaired limb but rather to functional compensation with the unimpaired limb. Physical functioning is often not strictly concerned with the bodily effects of stroke as much as the lived aftereffects of stroke survival.

While whether or not one has the desire to eat, or must monitor what he eats is irrelevant for FIM rating, such issues of appetite and diet are of practical concern in the everyday lives of many independent stroke survivors. Case 6, a married 84 year-old non-Hispanic white with some college or technical school (income not provided), is another interesting outlier. Case 6 feels the diagnosis of stroke is incorrect due to a misunderstanding he had with a VA employee during a face-to-face interaction (this is discussed in detail in Chapter 9). This understanding of his health status may impact how he relates diet and appetite to self-care. Case 6 focuses on diet and appetite as it relates to his “middle aged spread,” rather than on how it has impacted his health status as someone who is recovering from a major illness. This may be primarily due to the participant not believing that he had, at least recently, a major health event. Case 6 is more concerned with gaining weight and the impact being overweight may have on his general health than the impact certain types of food or beverages may have on such things as blood pressure.
At this point in his recovery case 6 may think of doing a particular exercise or eating less junk food but he does not see any symptoms of ill health and so has decided that such diet and exercise regimens are not immediately pertinent or necessary. Case 6 also indicates the impact his local shopping activity has on his eating habits, as well as having a lady friend who lives down the street, Norma, always close by to help him cook and clean on a daily basis. Such statements indicate the overlap of lived actions that are separated and distinguished as different when analyzed as components of such scales as the FIM and FAI. The following extract illustrates how these types of eating, shopping, and interpersonal activities are linked with one another when someone describes daily life. Further, as the following extract form case 6’s interview informs us, he does not think much about being disabled because he does not see any symptoms of disablement.

Int: Do you have like a serious, I mean are you on a diet from a doctor, a prescribed diet?

Par: No, no. I'm on no kind of diet at all, I just eat whatever I please when I please.

Int: Uh-huh. Let's see. Do you think any more about your body now? In the past couple of months had-

Par: What do you mean, worry about it?

Int: Um, that's one aspect of it or just think, you know just think about it in any way, like wonder about it?

Par: Yeah, I look at it and wonder about 20 or 30 years ago, how I used to look.

Int: Um-hmm.

Par: And I say, "God, you're getting fat!"

Int: (laughs) I do that now and I'm only 27. But um, do you do that or do you, I mean do you think about those types of things?

Par: Yeah, I think about, well maybe I ought to start doin' such and such an exercise but I'll do that manana.
Int: Yep, yeah.

Par: But I think that's human nature.

Int: Yeah.

Par: Like for instance, uh, one time I was going down here to Dr. Nigel and he says, "You know, you are heavy". I said, "Yeah, and I know what's causin' it, too". He said, "What?" I said, "I love ice cream."

Int: Um-hmm.

Par: And, ah, Albertson’s down here, or Publix will always, well almost every weekend, they would have Breyer's ice cream on sale, two half-gallons for five dollars. Well, I'd go and buy two of 'em and I could eat 'em in two days.

Int: (laughs) Uh-huh.

Par: And so I cut that out. And what did I lose? About 15 pounds, wasn't it?

Norma: Hmm, ah, yeah, I guess it was close to that.

Par: Yeah, I took it off real fast. And I was pleased with that, see. Lost this middle-aged spread in the middle.

Int: Uh-huh.

Par: And it was, the, I mean things like that, yeah, I think about it that way.

Int: So more of a weight issue?

Par: Well, that's primarily what it is, but as far as becoming disabled or something like that, I don't give that much thought because I don't have any of the symptoms of it, see?

The extract from case 6’s narrative also illustrates some of the more collaborative aspects to qualitative interviewing. For example, when the participant discusses looking at himself now and thinking back to how he looked 20 or 30 years ago, concluding, “God, you’re getting fat,” the interviewer relates to this experience, even though the interviewer himself is “only 27.” The interviewer relates further with the participant in
putting off physical exercise. This time, instead of relating such practices to age, the participant concludes “that’s part of human nature.” The participant then discusses his weight issues linking it with a conversation he had with his physician. Ultimately the weight gain, however, is not related to other physiological aspects like stroke, resulting in decrease motor movement, but rather to the participant’s love of ice cream and the enticement of the local grocery’s 2 for 1 weekly special on his favorite brand.

The participant states that once curtailing his ice cream intake, he has lost 15 pounds. But when the interviewer mentions the participant not eating ice cream any longer, the participant says he still eats ice cream, providing an example of what he ate the night before. At the end of the extract, the participant forgets the brand name of a potato chip he enjoys eating. The interviewer provides the name for him. This again illustrates the collaborative effort between interviewer and respondent. It may be that more collaboration between interviewer and respondent can be seen in this extract than in other interviews included in the sample in part because the participant does not see himself as a “stroke survivor” or “disabled person,” but rather as the same person he’s always been, albeit a bit older and perhaps a bit wider, if not wiser. In the next extract from case 6’s interview, rather than a stroke survivor and a research investigator, the respondent and interviewer collaborate in describing the enjoyment and satisfaction of ingesting “junk food.”

Int:   Um-hmm. Are you worried that your weight might harm you, harm other health aspects of you?
Par:   Sometimes I think about that, yeah.
And to stay healthy, you said you stopped eating ice cream. Is there, are there any other things you do?

Oh, I have some ice cream occasionally now.

Um-hmm.

As a matter of fact I had some last night. She made an angel food cake-

Um-hmm.

- and brought me over a big slab of it and some Dairy Queen ice cream.

Um-hmm.

Had me a nice cup like that [illustrates the size of the cup with his hands]. I sat here last night and ate the thing and, the whole, all the chocolate ice cream and that slice of angel food cake, which I don't normally do at night, I mean, 'cause once I get through eating, that's it for the evening.

Um-hmm.

If I eat anything it would be munching, I mean I'll munch on something. Like junk food, you know. Um, what are those things with the triangle squares that you buy?

Oh, those salty things?

Yeah, they're so good. Taco flavored, you know. All the cheese in it.

Dorito's?

Four cheeses, is that the one?

Doritos.

Oh, Doritos.

Yeah, he knew exactly what I was talkin' about. He likes 'em, too.

(laughs)

Or peanuts. Yeah.

Cashews, peanuts.
**Shifts in Appetite**

While the first two cases presented in this section do not indicate any loss of appetite after their stroke event, many of the stroke survivors do express a decrease in appetite level and how appetite and diet impact their everyday life as it relates to bodily functioning. For instance case 1, a married 73 year-old African American who completed some high school and currently has an annual income between $15,000 - $25,000, discusses the importance of eating in the stroke recovery process. The participant describes his appetite as bad, with the extract provided below linking his bad appetite to a lack of physical strength, defining eating as a necessary component to living. In the following extract from case 1’s interview, he continues to wait for his appetite to return to normal, because as the participant states, “I’m just waitin’ on time, I know it take time.”

Par: My appetite is bad and this soreness feeling I had to go back for hip, it left, then it started back and then I continued taking the medicine. Now it's kinda half gone but not all the way yet. . . . The only thing, the worst thing that bother me, I know I can't be strong if I don't eat and I eat. I would like to eat a little more but I just don't want it.

Int: Right

Par: I go for a lot of things down there to eat, I know you got to eat to live.

Int: Um-hm. Now we talked about good days earlier, like what is a good day for you. How do the good days affect your feelings about the way your body works?

Par: This, well I had to acknowledge it takes time, anything that you set your mind to, just do that or not do nothin'. I'm just waitin' on time, I know it take time. So, yes, I feel but I just don't get hungry.

Int: Right.

Par: My appetite seems to be the worst off now.
Like case 1, case 19 also discusses a change in appetite after stroke. Case 19, a married 57 year-old African American who completed some college or technical school and currently has an annual income between $15,000-$25,000, informs the interviewer that whether or not he eats at all in the morning is dependent upon two major factors. As the following extract from case 19’s interview indicates, these factors are not his ability to lift a fork to his mouth, chew and swallow, as measured by the FIM, but rather his appetite and his wife.

Int: When you get up in the morning, what do you do?
Par: Oh. I wash up, take my pills and I have, drink some coffee, and have, have breakfast if I feel like eating. Some mornings I just don't feel like eating, uh cause I normally, I don't feel hungry. Unless she, uh, what do you, uh, unless she keeps uh, harpin' on it. Then I'll eat somethin' even if I don't want it.

Int: So she'll tell you to eat?
Par: Yeah.

The participant conveys to the interviewer that he probably would have fairly poor eating habits without his wife “harpin’” on him to eat something. Thus, while case 19 is completely independent in getting the food to his mouth and digesting it when he eats, he routinely requires supervision and coaxing by his caregiver to get him to the point where he begins eating. In other words, although cases 1 and 19 are completely independent in the hand and mouth processes of eating, they routinely face eating difficulties due to appetite fluctuations.

As case 19 reflects back upon life before his stroke, he also discusses the importance of appetite in staying healthy. Looking back on how he has taken care of himself throughout his life, the participant considers issues of diet and appetite such as skipping meals due to a rigorous work ethic, as well as focusing on the type of beverages
he drank (soda) and did not drink (water). While his work environment is used as a factor in his poor eating habits of the past, case 19’s environment also plays a key role in structuring his selection of beverages, but for different reasons. As the participant tells the interviewer, when he moved “down here” he was informed by the water company to boil water prior to ingestion. The participant figured that if he had to boil it he might as well brew coffee or tea. In this way his lack of drinking “plain water” is not entirely a personal preference. Environmental factors play into this limitation. The participant compares his former living location, New York, where he did drink plain water, to his current living location, where he drinks very little plain water. In the next extract, the participant expresses that he is currently attempting to negate these environmental factors by purchasing bottled water rather than drinking water from his home faucet, mentioning that he and his wife still only drink one bottle.

Int: Looking back on things, is there anything you think you would do differently now because of, um, of what you know?

Par: I probably, no I can't say that because I don't do it now. I don't know. If, I might've, no, I no, my habits were just too bad. I probably wouldn't do any, probably wouldn't have done anything different.

Int: Anything you wish you had done differently?

Par: Oh, yeah.

Int: What do you wish you had done differently?

Par: Quite a few things (laughs). Probably one, I wouldn't have came, moved down here; two, ah, but since I'm here, I would've probably taken better care of myself.

Int: How so?

Par: Uh, I probably would've worked the same but I would've (pause) ah, taken better care of myself as far as the way I eat ‘cause there was nights, I mean there was days that went by that if I, if I didn't, you know like when I was workin', I didn't eat. ‘Cause I didn't want to take the time out from work to eat. Even at lunchtime
on the job I would be still workin'. . . . And I probably wouldn't have drank so much soda and ate as much candy and snacks as I ah, knew I shouldn't have had because even, even up until I went into the hospital the first time for the diabetic ulcer I was still eatin' candy and drinkin' bottles and bottles of soda, coffee all night or so depending on what I was doin'. What part of the night I was in. Like when I was doin' the floors in the supermarket I'd be drinkin' soda. And I'd try, you know, 'cause I, never, I didn't drink water. The amount of water I'd drink in the 18 years I was here wouldn't even fill a bathtub. Cause I don't drink water. I don't drink plain water.

Int: Do you drink more water now?

Par: Yeah, I got in it, yeah I try to now. Ah, well still we don’t drink too much plain water, only one bottle. But I try to drink, drink more water than what I normally do cause I mean there were months and years when I didn't have any plain water.

Int: Months that you wouldn't drink water at all?

Par: Not plain water, I mean, I might drink Kool-Aid, I drink coffee, I drink tea, but not plain water. Cause I didn't like the taste of water. And I think, I think what the main thing that turned me off of it is when we came down here and the first thing I saw when I moved down here, first thing I got was from the water company. Boil your water before drinking. And I'm paying these people for water and I got, I gotta boil it before I can drink it? You know, so I just said I won't bother with it at all. If I gotta boil the water I may as well make tea or coffee or somethin' like that. But, I didn't have that, I drank a lot of water in New York, but I just didn't drink any here.

Like that of case 19, the issue of consuming water and the environmental reasons that have impacted such consumption patterns is also used as a narrative resource by case 23, a married 67 year-old African American high school graduate whose current annual income is less than $15,000. Due to mistrust of the water company case 23 doesn’t drink much water, stating that the water company puts arsenic in the water. In this participant’s narrative something considered healthy to ingest is made unhealthy through the water company’s decision to taint the normally healthy resource with unhealthy chemicals. Both case 19 and case 23 reflect on their lack of water drinking as a practical action taken by them due to the level of contamination in their water supply.
Case 23 also informs the interviewer that he isn’t healthy; he’s just alive. He has high blood pressure and high cholesterol. When asked about his diet and appetite case 23 states that he eats less now, and then begins trying to recall if he has eaten today, concluding that he has indeed eaten, remembering that he had some leftover mashed potatoes, two fried eggs, and tuna. But the participant adds that eating or not eating doesn’t bother him. He’s always eaten starch and continues to do so. Through analyzing case 23’s narrative we find that he relates taking care of his blood pressure and cholesterol more closely to his medication regimen than to his diet or exercise routine.

Int: What do you do to stay healthy?

Par: I'm not healthy

Int: No?

Par: I'm not healthy. I'm just alive. Uh, my blood pressure is high. My cholesterol is high. Uh, I'm not healthy

Int: Are you doing anything to try to change this?

Par: Well they, they giving medication. Other than that…

Int: What about your diet?

Par: I eat less.

Int: Uh-uh

Par: Then I gain weight. I go sometimes like I haven't eaten. Did I eat today?

Int: But not like going on a diet like the type of food you eat?

Par: Well I'm trying to think did I (pause) okay I had some mashed potatoes from yesterday.

Int: Uh-uh

Par: On top of two fried eggs and some tuna.
Okay. Okay I did eat today. Okay (chuckles). Yeah and the next time I eat it may be just something to snack on. Something like that.

You know that eating doesn't bother me or not eating doesn't bother me. Right. I've always eaten starch. My sugar intake is ah... I don't drink as much water because I don't trust the water department. They put arsenic in the, in the water.

Whereas case 23 doesn’t worry about his diet or appetite, case 9, a divorced 52 year-old non-Hispanic white who graduated high school and currently has an annual income below $15,000, states that he does worry about such things. In relation to eating starches all your life, according to case 9, “you gotta back off.” In this way the below extract marks a clear distinction between case 23 and case 9. Case 23 does not see a need to change his everyday routine of eating fried eggs and mashed potatoes, and sees little problem in having an irregular eating schedule. The medication will take care of his blood pressure and cholesterol problems. For case 9, such statements as the ones made by case 23 are representative of one who is “giving up,” and according to him, “that’s the worst thing a man can do.” For case 9 one must impose his personal will to combat the effects of medication and/or illness. Not eating due to lack of appetite is seen as giving up and letting “them” win.

You know, that I really kind of worry about it, and, and you gotta back off on the, ah, sugars and, uh, starches, change your, uh, your menu. . . . And let your doctor know what you're eating, what you're doin', and there's a great possibility of everything workin'. But, uh, just because you have strokes, or seizures, or
anything like that, you don't give up. I mean Hell, that's the worst thing a man can do. . . . No. Dilantin shut me down. I couldn't eat, I had no desire to eat and Hell I'd go, I went a week without eatin'. Yeah. Why, I'll eat. If you quit, they win. That's, that's always been my thing. You quit, they're gonna win. Now where's the fight in you?

Case 22, a divorced 66 year-old non-Hispanic white who attended some college or technical school with a current annual income below $15,000, has also decided to alter his diet, as well as cutting down drastically on smoking tobacco and no longer drinking alcoholic beverages. This participant states that he exerts his dietary will through resisting the temptation of cheap fast-food, similar to case 6’s discussion regarding his cutting down of ice-cream ingestion. The extract makes a clear distinction between what he does now to what he did before.

Int: What do you do to stay healthy?
Par: Now?
Int: Yep.
Par: Well let’s see. . . I curtailed smoking. It’s out except for my sneaking one or two a day. Umm I don't drink. And I'm givin’ up like fried foods and stuff like that you know I'm not gonna go to McDonalds and get any of their burgers umm when they have those sales.

Co-morbidities, and in particular high blood pressure, high cholesterol and diabetes, impacts the way people relate dietary practice to self-care activity. Case 23 states that he is not healthy due to high blood pressure and high cholesterol, but he relies primarily on medication as a means of caring for these health factors, continuing to eat fried eggs and mashed potatoes if he desires because as the participant indicates, food or lack of food has never bothered him and it still doesn’t. Case 19, however, reflects back on his past behavior, discussing being diagnosed with a diabetic ulcer and continuing to eat candy and drink soda and coffee instead of water. This biographical information is
used by the participant as a way of indicating how he has failed at self-care throughout his life. Case 22 uses similar biographical markers; only instead of soda and candy his old “bad” self-care habits are cigarettes and hamburgers. While soda, candy, cigarettes, and Big Macs may offer the body immediate gratification in the form of taste and physiological sensation, in the long run these types of stimuli are used as examples of “bad habits” that actually impede successful self-care practices. Yet, there still exist some, such as case 6 and his interviewer, who resist strict dietary regimen.

In the next extract, case 8, a married 65 year-old African American who attended some college or technical school (income not specified), discusses the impact diabetes has on his eating behavior and how such dietary considerations are a result of who he is, stating “I am a diabetic.” Rather than informing the interviewer he has diabetes, that is, as a condition imposing itself upon him, he relates who he is with the disease “I am a diabetic.” Thus, diet not only helps to control the disease, it also controls the self. His self-will in essence is his dietary will. It is this dietary will that enables him to “control” his cholesterol and perhaps helps him stay off of insulin. His will, however, can only go so far. Where it stops, medical science comes in. The participant notes that he takes medication to help control his blood pressure, concluding, “that’s my life commitment right there now. That’s what I have to do.”

Par: I don't know whether I could say that's because of my diabetes, you understand, which I am a diabetic. And I'm on, controlled with, ah, diet control.

Int: Okay.

Par: But I'm not on insulin. I'm not on insulin. Thank God I'm not on insulin…Well, the future look like to me, (pause) that I have to be very careful about what I eat. I have to maintain myself on a low-fat diet, that's to control my cholesterol. Ah, I have to be on the medication to control my hypertension, (long pause) and that's it, that's my life commitment right there now. That's what I have to do.
In analyzing eating practices and how they relate to self-care, a distinction seems to be made between imposing one’s own will of dietary control and “giving up,” accepting one’s health conditions, at best passing one’s will over to medical science in the form of medication scheduling. The “fighter” may still take medications, but he is also, and foremost, attempting to self control certain health conditions through implementation of dietary will. The one who gives up is one who does not impose his dietary will, simply ingesting medications and waiting for the combination of pharmaceuticals and time to change one’s physiological condition for the better. The fighter, adopts a dietary regimen, which will, with the aid of medication and perhaps even a little exercise, optimize bodily health.

The use of the term dietary will is used here to express an active self that takes control as opposed to a passive self that gives up control to medicine and fate. However, there are those, such as case 6, who actively decide to eat what they choose, null of dietary considerations. A more practical term to use in describing the intersection of the active and passive self is that of dietary monitoring, where one takes active note on ingestion practices, but does so with a medical gaze. Where dietary will may be a clear self-act of exerting one’s own life knowledge regarding good self-care practices, dietary monitoring may be used to express a self that acts as a conduit between medical knowledge and dietary self-care activities. The following two extracts from cases 24 (married 59 year-old non-Hispanic white, h.s. graduate; annual income between $35,001-$45,000) and 29 (married 55 year-old Puerto-Rican Hispanic, some college or technical school; annual income between $25,001-$35,000) respectively seem to indicate a change in self-care practices after their stroke event. While these two cases do not overtly
mention implementing medical knowledge, eating better and exercising as complements
to taking medication are used as activities one should now be performing.

[Case 24]

Par: No there's no up side to this except monitoring my health more closely. Ahh the
blood pressure was rising but you know the doctors weren't too concerned. At the
time they were giving me medication and mostly it was under control but
evidently it wasn't low enough, you know. I should of probably maybe got more
exercise. Maybe got more dieting or something.

[Case 29]

Int: What do you do to stay healthy?
Par: Just eat better, make sure that I take my medication on time every day, sleep as
well as I can, and exercise.

Communicating Dietary Knowledge

Cases 24 and 29 seem to recite the mantra without naming the guru. Case 7
(married 70 year-old non-Hispanic white with some college or technical school, annual
income less than $15,000) on the other hand, details how in accordance with direct
medical guidance he has changed his diet since having major heart surgery in 1993.
Although recently having a mini stroke episode that resulted in another surgery to clear a
carotid artery, case 7 relates his major health episode with the implementation of an
artificial heart valve inside his body. It is not the stroke case 7 sees himself surviving
from, primarily because, as he expresses, medical science prevented a “full-blown
stroke.” Rather, case 7 sees himself a survivor from the major heart surgery he had 8
years prior. According to case 7, cholesterol is at the center of his health problems. As
the following extract illustrates, the stroke survivor’s cholesterol must be controlled, and
this is done so through the adherence of a strict dietary regimen.

Int: Do you think there's anything unique to your background that influences how you
feel about having a mini stroke, or the [recent neck] surgery?
The only thing I can think of would be, ah, as I look back, I probably could've changed my diet somewhat years ago and maybe avoided it altogether. Other than that, I don't know of anything.

So the diet, your eating habits?

I think the eating habits, which has changed now, of course, obviously since I had my heart problem, but, ah, before that time I think if I'd had a different, a little bit different practice of eating I think it would've been, probably helpful in this deal, wouldn't have, maybe wouldn't even had to have this operation.

You think your eating habits prior to 1993 might have impacted it? What were those habits?

Well, I mean, I didn't even, I had never been to the doctor since, 'til '93. And, ah, for 62 years I just pretty well eat what I wanted to eat and, you know, I didn't, I just did my own thing, so if I'd a had, if I'd a went did some, made some visits to the doctors and so forth and had some tests made, ah, I probably would've known that my cholesterol was high and all that kind of stuff and could've done something earlier in life that would've prevented this and probably would've even prevented my heart valve from goin' bad cause it was calciumed-up too. That's what was wrong with it. Just a matter of calcium which, I guess from what I understand, is cholesterol.

Do you think there's certain food that impacted your cholesterol?

Oh yeah, 'cause I eat eggs, eggs, ah, oh for years and years and years. That was my big meal in the morning was eggs and all that stuff, plus grease and, you know. But, ah, since that heart problem then we changed all of our eating habits, which probably helped my wife, too (laughs).

How did you change 'em? What do you do now?

Well, a low fat diet, and ah, cholesterol, prostate and cholesterol medication, too.

What types of things do you eat now that you might not have eaten? I mean, are there different things that you eat now, or do you just eat less eggs?

Well, it's the way, oh yeah, I don't eat hardly any eggs. It's, um, the preparation of the food, the way we prepare it is different.

You use less oil?

Yeah, less grease and all that kind of stuff. And, ah, which all has a big impact on it, plus the things that I eat. I eat more fish and more of that kind of food than I
do, um, the red meat and all that which we used to just about always eat all red meat. Everything we did was wrong (laughs).

Int: Everything you did was wrong? Did someone tell you that or is that your own conclusion?

Par: Yeah, oh yeah. Yeah, when I had that heart operation, of course they changed me all around and give us a list of stuff we should eat, shouldn't eat and ways to prepare it and all that. Low salt diet and all that.

Int: They gave you a list and you followed the list is that right?

Par: Yeah, um-hm.

Bryan Turner (1982) discusses the discourse of diet, noting that dietary regimen is an obvious form of control exercised over bodies with the aim of establishing a discipline. Such a medical diet as the one discussed by case 7 can be seen as a government of the body. It offers a system of rationalization over the body. Medication and surgery are to be secondary treatments to the body. The first treatment is dietary regulation, where the pipes, pumps, and passages, of the body are maintained via the appropriate supply of the appropriate kinds of food and liquid. Case 7 eats fewer eggs and more fish. He and his wife use less grease and salt in preparing meals. Previously they had eaten quite a bit of red meat, which was “wrong” for them to do. As case 7 states, “everything we did was wrong.” This moral determination was aided by medical knowledge; a knowledge that now serves as a resource in determining case 7, and perhaps by default, his wife’s eating practices. According to dietary discourse, such foods as hamburgers, starches, candy, and eggs are bad. Beverages like soda, coffee, and beer are bad. A low-fat, low salt diet with lots of water and a bit of medication and exercise is good bodily practice according to those adhering to a dietary regimen.
It is in dietary regulation where medical regimen and religious asceticism intersect (Turner 1982). Even the expressed importance of “clean water,” as indicated in the narratives of cases 19 and 23, can be dated back to early western capitalism of the 19th century, where illness was to be controlled by an individualistic moral control of impurity. Cases 19 and 23 express that due to an inadequate water system and rigorous work schedule, at least some of the moral control over the body was out of their “hands.” This moral control, however, is a scientific disciplining of protein and caloric regulation, where body mechanics are broken down and scrutinized. The hedonistic passion for ice cream, potato chips, candy, soda, steak, tobacco and liquor must be tamed through the dietary regimentation of self-will. The only moderately functioning participant included in this section, case 13, a married 51 year-old African-American college graduate with current annual income between $35,001 to $45,000, presents an interesting example of how one’s own dietary will, if contradictory to medical discourse, must succumb to a new bodily consumption regimen. This physical succumbing to a new consumption pattern is illustrated in the following extract from case 13’s interview.

Int: Um-hmm. So in what ways would you say that your stroke has changed what life means to you now? We're lookin' at those differences.

Par: It changed a lot 'cause I love to drink beer. I can't drink no alcohol. I'm about to have a fit 'cause I can't drink them. Thought I’d ask the doctor about it yesterday, he say, "Yeah I know you ain't been drinkin' no alcohol?" I said, "No". Golly that hurt. I was gonna ask if I could have one every week. He said, "oh, okay good", and that changed and then I had to make sure I take my medicine all the time.

As seen in the extracts presented to this point, it is not only in alcohol consumption that one’s personal preferences may come into conflict with expert knowledge. Dietary experts may also frown upon tobacco, red meat, dairy products, grease, salt, and
carbonated beverages. Also, one does not have to be a medical professional to share dietary expertise. In case 17’s (married 73 year-old African American college graduate annual income between $35,001 to $45,000) extract provided below we get a clearer connection between medical knowledge and the implementation of specific self-care practices such as “eating better” and exercising after experiencing a stroke event, and how the stroke survivor can inform others on the positive impact of proper diet.

**Int:** Has the stroke made you think more about your body and how your body works?

**Par:** Oh yes. Oh yes.

**Int:** How so?

**Par:** I've got medical books up the gazoo. I'm looking, I'm, the moment I hear something or if I see something on TV I go get my medical book and I look at it and I read it. Like a friend of mine has the gout real bad and I'm able to tell him what he should do what he should not do, what he should eat what he should not eat because I can encourage him. The hospital is no place to make enemies, you know. And if there's something that you want to eat, tell the doctor what you want to eat. Are you satisfied with what you're eating? Tell the doctor. But he'll let you know whether or not you can eat it or not. He'll send a nutritionist up and the nutritionist can tell whether or not, and he'll tell you why. And don't forget to ask why. Why this? Why that? Why, you know, don't forget to always ask questions.

Case 17 conveys to us how the self-act and the self-as-conduit interrelate. That is, a person may decide for herself that the food she is eating is non-satisfactory. But it is not up to herself to eat something different. It is up to herself to consult the doctor and in turn the doctor will send for the expert, the nutritionist. Ultimately it is medical knowledge that decides, but one’s self must always monitor medical knowledge as well as personal bodily practices. Such monitoring is accomplished by always asking questions. Yet these questions are more of a re-orientation of the self as it relates to eating than they are a watchdog of the medical gaze. That is, the questions of the doctor
are a way to receive the correct and proper information rather than a way to see if one actually agrees with what the expert is dictating. Case 17 also details how his interactions with medical knowledge enable him to share such knowledge with those he interacts with outside the hospital or clinic. Through the use of medical books and television, case 17 is able to take the narrative position of physician in informing his friend how to monitor his diet when dealing with gout. A similar position is taken by case 31, a divorced 69 year-old Puerto-Rican Hispanic with a high school diploma and an annual income below $15,000. When his nephew comes over to visit after going to the hospital due to dizziness caused by high blood pressure, case 31 tells his nephew to “take care of himself,” and then proceeds to inform his nephew on how to do so. The information provided in the following extract involves dietary will, such as not using salt or drinking beer, as well as more direct medical adherence, that is, always taking his medication.

Par: Yesterday, one of my nephews was here. Previously, he had experienced dizziness due to high blood pressure. In the hospital they give him pills. I told him to take care of himself. To look at me. He is taking his pills daily. He used to drink, and doesn't do it anymore. I told him that that could be very helpful.

Int: Yes.

Par: Above all, to stop the use of salt, beer, which is non productive, and to always take his pills.

Case 31 tells his nephew to “look at him.” Case 31 uses his body as a material symbol of poor dietary will, that is it is the corporeal presence of non-adherence to medical discourse. Case 31 didn’t listen, the result of which is his current health status. His nephew is to take this bodily symbol as well as the recent dizziness due to high blood pressure as precursors to future health events if the nephew does not discipline his self.
The way to prevent future illness experiences is to implement the proper diet, stop consuming alcohol, and take prescribed medication; to give one’s self over to medical discourse via bodily practices that are in alignment with medical expertise.

The final example provided in discussing the lived experience of eating for stroke survivors is case 28, a divorced 54 year-old African American with some college or technical school with an annual income between $25,001-$35,000. Case 28 informs us that eating habits are very important to one’s health status. Case 28’s friend Joe also notes the cultural differences in eating habits, as well as the cultural differences in living environment and how others perceive these differences, stating that such living arrangements and social stigma may also have a negative impact on a group’s general health status in comparison to the dominant, non-stigmatized group. Case 28 presents a complex narrative that intertwines eating with cultural, racial, and gender identification. Such an intertwining of various complicated factors is presented in the next extract, illustrating the importance of diet and appetite in the lived experience of all of us, including stroke survivors.

Par: Do not worry, 'cause to me I believe that worryin' brings it down on you, you know?

Int: Um-hmm.

Par: It have somethin' to do with it comin' down on you, you know?

Int: Um-hmm.

Par: And then depend on what you eat and how you eat.

Int: That's true.

Par: And, and the rest you get. Yeah. And then, get off at 3:30, get home about 4, 4:15. Like I say, I get somethin' to eat, sometimes I don't eat.
Int: Okay. Now do you find that you focus on your body more now that you did before you had your stroke?

Par: I do.

Int: You do?

Par: Um-hmm.

Int: Okay. Are there particular parts of your body that you focus on?

Par: Yeah I watch, like my weight, you know, my leg, and arm and chest, you know I try to see how much weight I done lost or do I look thin or do I look like I'm still kind of masculine you know.

Int: Right.

Joe: He eats.

Par: Yeah (Laughs).

Int: (Laughs) Ain't skippin' on no meals, that's good.

Par: Yeah, but-

Int: Now, go ahead.

Par: I'm satisfied though with how it's lookin' now.

Int: Oh your body? Okay, good. Now are there things you learned on your own that makes your, that makes your body work better?

Par: Ah, well I think exercise.

As well as relating the importance of what and how one eats to personal health, case 28 also discusses the drinking of plenty of water, attempting to get proper rest and exercise, and how this relates to his general satisfaction with how his body looks. Due to an active social life and a workday that involves interpersonal turmoil that case 28 relates to his being African-American, the participant believes that lack of rest may have strongly impacted his recent episodes of poor health. At present, however, case 28
concludes that he’s pretty satisfied with how it’s looking (his body), telling the interviewer that he still looks fairly masculine. In the next extract, others such as his good friend Joe aid his body image and the regulation and maintenance of his bodily practices by providing dietary information, not only monitoring case 28’s food intake, but also attempting to help case 28 drink proper fluids like Hi-C.

Int: And what do you do to stay healthy? You told me you exercise a little bit.
Par: Yeah I exercise a little bit. I drink plenty water now.
Int: Uh-huh.
Par: And I got so I eat those Healthy Choice and try to eat right.
Int: Right.
Par: (Chuckles) 'Cause every time I go in Publix I try to buy 'em all and they (Laughs) you know. And I listen to people, you know, like uh, tellin' me what type of sodas to drink and all that.
Int: Right.
Par: Even Joe told me, you know-
Joe: I be round here on him.
Par: Drink somethin' like Hi-C.
Int: Be on him (Laughs)
Joe: Hi-C or Hawaiian Punch.

Case 28 discusses how his dietary regimen impacts his interaction in a particular public setting; the grocery store. As he purchases a large amount of “health food,” those around him try to provide him with information regarding the “right” types of beverages to consume. Thus not only close friends like Joe provide case 28 with dietary information, but others in the public environment who otherwise have little personal
contact with the participant, also are readily willing to provide information regarding
dietary rules and regulations. When case 28 is asked about how he thinks race and
ethnicity factor into the stroke recovery experience his friend Joe rejoins the
conversation, asking the interviewer, the expert in the setting, if it is true that certain
minority groups are more prone to strokes due to eating a large amount of pork, being
overworked, living in unsanitary environments, and “being thought of as dirty.” This
question indicates the lived complexities of healthy and unhealthy situations, as well as
how medical discourse is utilized as a narrative resource in discussing daily life of
different groups of people.

Joe’s question is first a statement marking a difference between the dominant white
lifestyle and the minority “black, Mexican and Indian lifestyles.” With this difference in
lifestyle marked, the question becomes if the differences between these lifestyles impact
the differences in white and minority health status, particularly as it relates to stroke
onset. Further, in the following extract lifestyle is directly related to food consumption,
labor, environmental, and social perception patterns.

Joe: Is it true that blacks, because of uh, our lifestyles and, and what we consume, is it
true that Mexicans, Indians and blacks are prone more to strokes, because all the
pork and because the added stress of 2 or 3 jobs, growin' up in the
hood, and you know all of bein' thought of as dirty?

This section has illustrated how eating as it is involved in everyday functioning
often involves much more than the use of hand and mouth. Diet, appetite, co-morbidities,
enjoyment of alcohol, soda, and fatty foods, acceptance of expert knowledge, and the
expressed knowledge of how eating may or may not impact overall bodily functioning,
all play a part in how high functioning stroke survivors come to experience the task of
eating and drinking in their everyday lives. While these issues are not addressed in
functional measures, they often are the factors expressed as being of most importance in how life has changed for high functioning stroke survivors. Interestingly, out of all the cases included in this section, only one, case 13, is representative of the moderately functioning group. All others who discussed the importance of diet and appetite in self-care were high functioning participants. If one is attempting to capture the shifts and changes in the recovery process, particularly for those survivors whose daily concerns are not captured by a measurement tool like the FIM, such issues as diet and appetite, and how medical knowledge relates to the lived body, must be addressed.

**Medication Maintenance**

A review of the extracts included in the section on eating reveals various aspects to daily living that go beyond the complexities of food consumption. Medication maintenance is an aspect discussed by many of the participants as an important self-care task that is commonly linked with the discussion of eating. This may be because medication regimens often require medication ingestion immediately before or after eating a substantive meal. For many of the participants, daily life is expressed in terms of eating, resting and taking one’s medicine. A rudimentary glance at this information may lead one to conclude that these participants live inactive lives. Often such conclusions are drawn in comparison to a normal lifestyle where watching television, napping, and taking it easy are seen as economically unproductive, thus somehow unhealthy life activities.

If such preconceived understandings of activity/inactivity are set aside when analyzing the everyday lives of these stroke survivors, various mundane components to life that may commonly be seen as uninteresting, taken-for-granted aspects to an inactive life become much more than that. The various reflections on eating and medication
intake indicate complexities in situations often glossed over as practically irrelevant. This practical irrelevance is derived from research considerations formed outside of the lived experience of the people under consideration. Once the lived experiences of those being studied are dealt with in their own terms, what is commonly seen as uninteresting often takes on practical relevance, which if investigating the everyday lives of stroke survivors who are living in the community, also takes on social-scientific relevance.

Medication regimen is one aspect to self-care often taken-for-granted by research investigators that offers practical insight into the lived experiences of such groups of people as moderately high-functioning stroke survivors who have returned home.

**Medication as an Unquestioned Routine**

Case 28 offers a clear depiction of his medication regimen before and after the stroke event, indicating a major difference in his everyday routine activities as well as a shift in his embodied self. His extract begins discussing the stroke event. The interviewer asks if he thought about taking some Tylenol. Case 28 answers that he thought about it but he never takes Tylenol or aspirin. He then adds that he takes an aspirin “once every full-moon.” In the next extract provided from case 28’s interview, the stroke survivor explains why he does this, stating, “a few say it’s good for your heart attacks and stuff,” indicating a certain level of adherence to medical information that may be provided by media, face-to-face interaction with experts, or communicative exchanges with laypeople who are in the know. Case 28 concludes by saying that he never did take a lot of medication until he started up with the VA. Now he takes medication on a routine basis “for blood pressure and that thing.”

Par: I was sleepin'. I thought maybe my head was crooked. I wasn't sleepin' straight like this. And right back here I had some pain all in my neck.
Int: Really?

Par: Yeah. I wonder what that was, maybe just a headache, you know?

Int: Right.

Par: No, but it's just the neck.

Int: How did you relieve it? I mean…

Par: Well I guess I had a what you call a mini stroke and it went away.

Int: Just went away? Did you, did you think of tryin' to take me some Tylenol, somethin' to get…

Par: Well yeah, but one thing about 'em I don't take Tylenol and aspirins. But uh, I take a aspirin like once every full moon. A few say it good for your heart attacks and stuff, I mean…

Int: Right, right, um-hmm.

Par: And I'll do that and I, but I never took a lot of medicine 'til I started with the VA, and that's when I started takin' medicine for blood pressure and that thing.

Similar to dietary regimen, medical knowledge also impacts medication intake.

These moderate-to-high functioning stroke survivors, however, reflect upon the ingestion of a wide-variety of medication in different ways. Many of the participants simply list taking medication as one activity they perform in everyday life, with the activity not dealt with in much detail beyond that. For others, medication regimen is of paramount concern in their lived experiences. Case 28 seems not to question his change in medication regimen, simply stating that he now takes medication he previously never thought of taking until told by VA employees that it will help control his blood pressure. Case 8 offers a similar example, stating that eating “right” and taking his medicine is his “life commitment right there… that’s what I have to do.”
Case 8’s extract also intimately links his dietary regimen to his medication routine. Linked to being both a diabetic and a stroke survivor, his life commitment deals with eating the proper food and taking the proper medicine. What is proper is understood to be what medical professionals tell him is proper. Thus, case 8’s life commitment right now is adhering to expert knowledge. Case 8 tells the interviewer that his medication intake is a “lifetime situation.” It is this medicine that will prevent him from having another stroke. The medication is his protection. In the next extract, when asked if this medication intake is a burden, case 8 says no, he has to be satisfied with it because things could have been worse from the beginning. He has to “accept the things I cannot change.” Thus, taking prescribed medication is a way to transfer one’s bodily control to the expertise of medical professionals. Some stroke survivors, like cases 8 and 28, accept this as a necessary component to their everyday lived experience.

Par: Well, the future look like to me, (pause) that I have to be very careful about what I eat. I have to maintain myself on a low-fat diet, that's to control my cholesterol. Ah, I have to be on the medication to control my hypertension, (long pause) and that's it, that's my life commitment right there how, that's what I have to do. . . . after that, ah, I eat my breakfast. I take my medication and then, then. . . . I put them in the microwave, you know, for my lunch. I, ah, take my glucose. I have my glucose, and I take it at noontime and I eat my… and I eat supper and then take my medication, and, um, back on the computer (laughs) . . . But I, I want to say this, I want to say this here, this is just the beginning of it, the stroke. And this medication that they put me on it, it's for the protection, to prevent from me havin' another stroke.

Int: Oh, okay.

Par: So, actually this is a lifetime situation that ah, I'm involved in as far as medication is concerned. So...

Int: Does that seem like a burden to you or are you okay with that?

Par: No, but I have to be satisfied with it. Because the reason I have to be satisfied with it, it could have been worse.
Int: That's true.
Par: From the beginning.
Int: Right.
Par: So I have to accept the things I cannot change.

While not “okay” with having a seemingly infinite medication routine, case 8 says that he has no alternative but to be satisfied that such bodily reliance upon pharmaceutical regulation is something he cannot change. Case 8 not only adheres to expert knowledge regarding medication maintenance, but when advising others he takes the position of the expert telling those around him to take their medication as directed. The interviewer agrees that this is very important to do, then inquires if there is anything else case 8 would tell other veterans having just experienced a stroke. Case 8 answers that he’d wish them luck, tell them to take their problems to the Lord and take their medication. Each of these three actions give bodily determination to entities that are external to the embodied self; namely fate, God and medical knowledge. As the following extract from case 8’s interview illustrates, whereas dietary regimen seems to be expressed as an act of self-will in which the person attempts to make his body stronger through rigorous control of food and beverage consumption, medication regimen is described as taking a more passive position to recovery, giving one’s self over to the hands of more powerful forces; namely God and medicine.

Par: In other words, you're trying, I'm trying to, I have to compare my, my sympathies (pause) ah, my symptoms. What advice I would give him is ah, if he's ah, in, on any medication I'm quite sure he probably would be on any medication, just, I advise him that he take his medication.

Int: Yes. That's very important.
Par: Um-hmm.
Int: Anything else you can think of that you would want to tell someone since you've been there before? Something you want to advise him about if he were on his way home after having a stroke?

Par: (pause) Right now, I know I already stated it, is if that, I would just wish him luck and just tell him, you know, take his problems to the Lord. That's it. And take your medication.

In the following extract, this form of physically passive recovery indicated by case 8 is directly linked to one’s sense of self, full-personhood, and embodiment. When asked if he sees himself any differently as a person since he’s had a stroke case 8 answers no. He then describes his medical experiences that start upon his return from Vietnam. His first experience with the VA concerned his diagnosis with hypertension and the beginning of a medication regimen. Case 8 then informs the interviewer that he expected something would happen since he had to increase his medication dosage due to his body gradually becoming immune to the initially prescribed amount of chemicals. Thus not only does his medication maintain his health, it also presents him with health risks. These relatively high functioning stroke survivors commonly express this pharmaceutical paradox throughout their narratives. Case 8 concludes that he doesn’t regret what has happened, does not feel any different about his self, and does not have low self-esteem. The stroke is something that’s happened and he has accepted it. “I have to.” This extract offers intriguing insight into the benefits and risks of a prolonged medication schedule, and the ways by which those involved in years of medication intake come to reflect upon the experience.

Int: Do you see yourself differently as a person now that you've had a stroke?

Par: No, I don't feel differently about myself because I had this stroke. Because (clears throat) I’ll give you some background of my medical. See, ah, after undergoing through the wars and everything, Viet Nam and etcetera, I came out
and in service connected of hypertension which I was on medication. So, I figured ah, eventually, you know, I was gonna have somethin' like that. They was tied to, with this medication, you know, they had to change the doses or somethin' like that over a period of years because the medication would probably, would got, that my body wouldn't, you know, got immune to it or something like this and etcetera. Now (pause) getting back to the answer to your question, I doesn't, I doesn't really doesn't regret this. I doesn't feel any different about myself. And I've still have, I'm still actually my, I don't have no low self-esteem as you, you are aware of that, right? (laughs) And, ah, really it's somethin' that happened that, I mean, I can accept it. I have to (coughs).

When asked about his current bodily concerns case 8 states that he’s most concerned about his organs such as his liver and kidneys. When the interviewer asks why he’s concerned with those parts of his body, case 8 again reflects on his medication maintenance. Yet in order to relieve the left-side pain he is experiencing since the stroke event case 8 informs he takes medication, specifically 800 milligrams of Motrin, even displaying the medication to the interviewer. Thus, his greatest bodily concerns are directly linked to his medication intake, as are his everyday, routine health practices. This paradox is what case 8 has decided to accept, for according to him there is no other choice. As case 8 reflects upon his everyday life, it becomes clear in the extract below that his embodied self is not only dependent upon medication but also constantly threatened by it.

Int: What are your greatest concerns about your body now?
Par: My greatest concern about my body now is my organs. My liver, my kidney.

Int: Okay, why are you concerned about that?
Par: My organs. I just call them my organs. Why? I'm concerned about that because of the medication. That's why.

Int: Now, was it over your whole body when you had the stroke or just on your left side?
Par: Just my left side.
Int: Okay. Do you experience much pain?

Par: Sure.

Int: Where?

Par: The left side. And I have the medication for the pain.

Int: Okay, so you take medication to relieve the pain?

Par: Yeah, I take (places medicine bottle on the table) medication for the pain. That's Motrin 800mg.

Int: Is there anything else you do to relieve pain, or does that usually help?

Par: Yes.

Int: Okay. What do you do to stay healthy?

Par: What do I do to stay healthy? I eat, I sleep (laughs) I do my proper, my proper exercise and take my medication.

In the previous section dealing with how the stroke survivors themselves experience the practicalities of eating, case 10 provides an in-depth reflection on the importance of what he eats to his sense of self, noting that he used to be called “Squirrelly” because of his love of chocolate covered peanuts. Case 10 tells the interviewer that his stroke was caused by high cholesterol. He now is taking medication for his high cholesterol, which the interviewer says is “good to know, it’s something they can control.” Here, not only are the survivors themselves adhering to medical expertise, but the interviewers also discuss such adherence to medical control as “good” self-practice. The interviewer sees the constant medical monitoring of the participant’s body not as an invisible all-penetrating gaze that coerces bodies into humble obedience, but rather as something that is simply “good.” In the following extract interviewer and participant collaboratively establish this medical adherence as good for the participant’s
practical health maintenance. Case 10 then goes into statements regarding dietary control, thus also representing the more self-active component to bodily maintenance, although like medication maintenance this physical practice also closely adheres to medical expertise.

Par: They're givin' me a pill now for cholesterol, that's what caused my stroke.

Int: Oh, is that what they're saying? The cholesterol?

Par: The cholesterol went too high.

Int: Okay. Well that's good to know, it's something that they can control-

Par: So now they give me a pill to keep my cholesterol down.

Int: So are they, um, are they going to recheck your cholesterol-

Par: Every time I go to the doctor they check it.

Int: Every time you go in? Okay, that's good.

Par: Make sure it's not too high. And ah I'm on cholest, a less cholesterol diet.

Int: Okay, a low cholesterol diet.

Par: And she has to be careful what she buys because, you can't fix it with cholesterol in it.

Int: So-

Par: No fried food.

Int: No fried food.

Par: As much as I love scrambled eggs.

Like the other cases presented thus far, case 1 describes how his everyday experiences center on going along with what the doctors tell him, in an attempt to “get results of the medicine.” He informs the interviewer that the results have been slow to come, however. In the following extract case 1 describes his hip soreness that seems to
come and go. Throughout the recovery process case 1 has continued taking his medicine.

He then describes visiting the hospital, where he waited for a rather long period of time, was advised to see another medical specialist, went through additional physical examination, and then given some more medication.

Par: I've just been trying to go along with it you know to get results of the medicine to see but it's been very slow. . . . My appetite is bad and this soreness feeling I had to go back for hip, it left, then it started back and then I continued taking the medicine. Now it's kinda half gone but not all the way yet. . . .I makes go by the way they tell me takin' my medicine…Well, just like when I went takin' that medicine, that soreness come over, that's why I went back and my doctor was sick and I had to go to energy care and I had a lady doctor and I had appointment 8:30, I was there but, you know, it takes time and he had his patient at 12 o'clock

Int: um-hmm

Par: So, after this soreness effect come on I was advised to go down to energy care in the VA hospital and I went through some more tests and things uh, she gave me some medicine. I think it done good.

When asked if the stroke has affected how case 1 views himself as a person, he responds that yes it has. Before the stroke he was more active in doing yard work and was generally more mobile in everyday routine practice. After the stroke case 1 is listening to medical experts, taking his medicine, and “laying quietly.” This statement once again links medical knowledge to medication regimen resulting in a more passive embodied self. In the extract below, case 1 relates being sick to physical inability to perform certain functional tasks, and more specifically refers to his stroke experience as an affliction that goes beyond behavior, with healing coming from rest, time, and the ingestion of pharmaceuticals.

Int: I just wanted to ask, has your stroke affected the way you feel about yourself as a person?

Par: Yes, right now it does, yes, it does.
Int: In what way?

Par: Well, uh, it's like this here, I'm goin' by like the doctor and takin' the medicine and layin' quietly. You understand me? Okay. Uh, it's things I need to be doin' but I let them go cause I know when you sick you ain't able.

Int: Hm-hm.

Par: And I say, for instance, I let my yard and things go off because I ain't able to do it. If it's a will it's a way if I have to get somebody to do it. . . . I don't, right now, I don't know if this affliction gonna cause me to be here for this. It's beyond behavior times, but the way I was, yes I'm better. Yes I is. I have to say so. I don't have to use a stick. Now this left side is not motivatin' like this side, now I can tell you that now. I take some medicine.

Much like case 8, case 1’s advice to other veterans who are faced with recovering from a stroke is to “do just like [your] advisor says,” that is, to bodily adhere to medical knowledge. Case 1’s point is that if the person’s self-knowledge had been “right” then he wouldn’t have gotten sick. Sickness is an indication of incorrect tacit knowledge in relation to one’s body. A stroke or other major illness is the material result of a faulty stock of knowledge as it pertains to maintaining a functional, healthy body. The following extract from case 1’s interview provides detail into what case 1 had been doing since he got sick. He now has given his self over to medical technology, doing what he’s told, taking his medication and “takin’ it easy.”

Int: So what would you tell [another veteran] to expect when he gets home?

Par: To do just like his advisor says and I think that's the best way to go. Don't go your way 'cause if your way would've been the right way you wouldn't had that sickness to start with. So, yes, I'm wants to go limitation in the doctor I take my medicine just like he said and, uh, yes I can't get out there and run from here to that road, no. . . .well, I can't speak beyond those because I ain't no medical technology, see, but uh, yes, I accepted what they done for me because it's like I told you, I'm copin' just like they give me the medicine to take and takin' it easy.
Medication as a Moral Enterprise

Many stroke survivors also distinguish between normal and abnormal medication use. For instance, case 7 discusses how he was instructed by medical personnel to take Tylenol after having surgery to clean out a carotid artery. Case 7 informs the interviewer that he only took 2 or 3 Tylenol and that this is the only over-the-counter medicine he has taken. What case 7 is conveying is that he doesn’t take medication, other than his “regular medicine,” that he takes normally. This brief extract from case 7’s interview, while perhaps seeming to be just a casual discussion of the use of pain relievers actually marks a clear distinction between what the stroke survivor finds to be normal regular pharmaceutical intake and what he finds to be abnormal, which is any type of pharmaceutical intake outside of what he’s been prescribed by a medical expert to help regulate his heart condition.

Int: How did it feel right after surgery? Did it hurt?
Par: Ah, not any more than what an incision would normally I don't guess. They told me to take Tylenol which I only took 2 or 3, I didn't take very many of ’em and, ah, I didn't take any pain pills.

Int: When you, if whenever you do experience any type of pain how do you usually reliefe it?
Par: Well, it depends on what it is, but I don't take much in the way of any over-the-counter medicine except Tylenol. And, uh, other than my regular medicine that I take normally. So I'm never havin' any pain of any kind.

With the tacit knowledge that one is to listen to the doctor and take whatever medication is prescribed to them, a rigorous medication regimen becomes part of the routine activities of everyday life for many stroke survivors. Case 7 notes that he was told to take Tylenol to relieve his pain post surgery, but only took a few. This non-adherence is resolved in his concluding remarks that he did take some, which differs from
his practices prior to being told by medical personnel to ingest this specific drug.

Furthermore, only taking a few was not necessarily disobeying the doctor’s orders because case 7 is “never havin’ any pain of any kind.” Thus, the Tylenol were just in case he experienced pain. Since he’s not feeling pain, it’s okay not to ingest the Tylenol. This differs from his normal medication, which he takes daily as prescribed.

In detailing his medication schedule, case 31 simply incorporates it into his everyday activities along with waking up, eating breakfast and watching television. Like some of the other examples provided to this point, case 31’s advice to other veterans going through a similar experience is to keep taking their medication. Case 31 states this “is the most important thing.” Continuing to take one’s medication is seen as a way of dealing with the current situation. Case 31 begins crying when taking stock of his current life situation, then, as provided in the previous section on eating, case 31 details how he gave medical advice to his nephew, instructing him on proper dietary practices as well as encouraging him to “always take his pills.” Case 31 seems to be following the advice provided earlier by case 1, doing just like his advisor says, deciding that's the best way to go. In the following extract case 31 reflects on informing his nephew not to go his own way in terms of diet, presumably because if his nephew’s way would've been the right way he would not have had the high blood pressure to begin with. Thus, one’s own ingestion practices may be “bad,” while medical expertise regarding dietary and medication intake strategies are “good.”

Int: So, you wake up, and come here to watch television and…

Par: And I eat breakfast, take my medicines, and sit down to watch television.

Int: Okay. What advice would you give to someone who is coming back home from the hospital after having a stroke?
Par: Do not stop taking their medication, that is the most important thing, and to try to deal with the situation, because many...how do you say it? They don't feel good...no, they don't even wish to live. Because they believe that's all there is to life.

Int: And, in your case?

Par: (Cries)

Daugther: Daddy, do not start crying.

Int: It's alright.

Par: (Crying. Takes a deep breath... Yesterday, one of my nephews was here. Previously, he had experienced dizziness due to high blood pressure. In the hospital they give them pills. I told him to take care of himself. To look at me. He is taking his pills daily. He used to drink, and doesn't do it anymore. I told him that that could be very helpful.

Int: Yes.

Par: Above all, to stop the use of salt, beer, which is non productive, and to always take his pills.

Int: You are already helping others, ah?

Par: And he is young, very young. He has young children. Mine are already grown, the youngest one is seventeen years old. So...

When case 31 informs the interviewer of the discussion he had with his nephew, the interviewer notes that the participant is already “helping others.” Suggesting to others that they adhere to medical discourse is thus seen as a helpful interpersonal activity.

Similar to the other extracts provided thus far in the current section on medication maintenance, case 29 discusses medication intake as part of his everyday routine activities. He takes a shower, eats breakfast, takes the medication he is “ordered” to take, and occasionally participates in physical exercise. In the below extract from case 29’s interview, when asked what he does to stay healthy case 29 discusses what many of the
stroke survivors discuss: eating better, ensuring they take all their medication on time, getting enough rest, and staying as physically active as possible. Thus, taking prescribed medication is seen as a “good”, “healthy” self-activity.

Par: I get up in the morning. I uhh take a shower. Then I eat some breakfast, take my medications that they order me, then the rest of the day I been basically running around. Sometimes I do physical, you know, I do exercise…

Int: What do you do to stay healthy?

Par: Just eat better, make sure that I take my medication on time every day, sleep as well as I can and exercise.

Case 18 also includes a brief discussion of medication maintenance as he details his daily routine. Like case 8, this participant displays an example of the pharmaceuticals he regularly ingests. In the following extract from case 18’s interview, the stroke survivor describes his day as bathing, taking his pills, reading his email, then going to sleep.

Int: What do you usually do in the morning?

Par: I bathe. I take all the pills.

Int: The pills?

Par: Including this one.

Int: Okay you first take your pills.

Par: And from there email.

Int: Then you see your email. Okay, and you respond to your email.

Par: Later, I fall asleep.

Like case 18, case 19’s extract describes his morning routine as washing up, taking medication, drinking coffee, and eating breakfast:

Int: When you get up in the morning, what do you do?
Oh. I wash up, take my pills and I have, drink some coffee, and have, have breakfast if I feel like eating. Some mornings I just don't feel like eating, uh cause I normally, I don't feel hungry. Unless she, uh, what do you, uh, unless she keeps uh, harpin' on it. Then I'll eat somethin' even if I don't want it.

As discussed in the previous section on eating, case 19’s spouse often “harps on him” to eat breakfast. Eating and medication schedules often overlap, but eating and medication also seem to be the two primary activities moderate to high functioning stroke survivors and their families monitor once the person recovering from stroke has returned home. Like case 19, case 23 has found that his appetite has decreased, perhaps a direct result from an increased medication regimen. Whereas case 19’s wife ensures he eats regularly, case 23’s wife does not “harp” on him. In stating that he’s not healthy due to high blood pressure and high cholesterol, case 23’s way of handling these experiences is to take the medicine that is prescribed to him. As he states, he is not healthy, he is “just alive,” further indicating a passive orientation to his embodied state. Case 23 also makes a clear distinction between the type of medication he takes for blood pressure and cholesterol and the medication other veterans he knows take for depression. He notes in the extract provided that he’s not depressed and as evidence of this indicates that he is not taking any medication for depression. Case 23 simply goes to listen to “them.” That is, he listens to other veterans who are depressed talk about their experiences.

So I would have to listen to them you know. I was listening to a lot of them downstairs today and they were talking about, well different topics, and one of the topics came up about medication and depression.

And stuff like that which I'm not depressed and I'm not taking medication for depression and stuff like that.
Par: Main thing that I do when I'm out here is I listen to them.

Int: Right. What do you do to stay healthy?

Par: I'm not healthy.

Int: No?

Par: I'm not healthy. I'm just alive. Uh my blood pressure is high, my cholesterol is high. Uh I'm not healthy.

Int: Are you doing anything to try to change this?

Par: Well they giving me medication. Other than that…

Int: What about your diet?

Par: Uh I eat less.

Like cases 7 and 23, some participants distinguish “normal” medication from other types of pharmaceuticals they do not routinely ingest. Many participants see this “normal” medical intake as a very important aspect to everyday life, often informing others that following one’s prescribed medication schedule is extremely beneficial to health maintenance. There also appears to be intimate links among diet, appetite, medication intake, and rest. For the few who find maintaining a strict schedule difficult, others in the home may provide monitoring assistance. For example, case 19’s spouse ensures he maintains a regular eating schedule. In a similar fashion, in the next extract from case 13’s interview, the stroke survivor’s spouse helps to monitor his medication schedule.

Int: Um-hmm. And does that make a difference for you if, when someone is here as opposed to earlier when you're alone?

Par: (laughs) It don't make no difference. (Pause) Was, she come home, she can help me with some things. She makes sure I take my medicine right.
Okay. Now some people, sometimes people feel that it's more of a burden after a stroke, some people don't. Now what, what's it like for you?

It, I feel like it's a burden to my wife 'cause she has to make sure that I take my medicine and she would help me do a lot of things and I say I'm used to doin' a lot of things for myself. But she helped me a lot of that so I, and she, I wish I shouldn't have to call her to do things. And then she'll make sure that I take my medicine. She'll say,"It's time to take your medicine". And then sometime we'll fuss a little bit and say things that, I mean, get on your nerves and I say Lord I'll be glad when I stay back to my house. That's the burden that, see, that she shouldn't have to worry about that.

So more fussing as far as things regarding, I guess, things associated with a stroke such as medication and stuff like that?

Yeah.

Similar to cases 25 and 31 whose living arrangements altered after returning home after the stroke event, case 13 who had previously lived separately from his wife, is now living with her so that she can care for him during his early recovery period. Case 13 sees this as a burden on his wife; a burden that she shouldn’t have to deal with. The example of this burden concerns the stroke survivor’s medication regimen, where case 13’s wife informs him that it is time to take his medication and case 13 resists ingesting the pharmaceuticals. As further indication of the ongoing negotiations concerning medication schedule, case 13 informs that it is not only his wife who monitors his medication intake, but other members of his family such as his daughter that tell him when to take medication and what type of fluids to drink while doing so. Rather than continuing to resist, case 13 says, “okay,” and takes his medicine. In the next extract, this form of family interaction is expressed by case 13 as how his family “helped me out a lot.”

Okay. Um, now tell me a bit about your, how your family is reacting to you since the stroke. Do you think they treat you differently?
Par: Um, uh, I remember when I had it, I know how bad they felt. And when I came home my daughter, she helped me out a lot. She always tell me, "Ain't it time to take your medicine? You're suppose to take it all now, drink all this juice now. Drink it now". I say, "Okay". No they don't treat me no different.

While the stroke survivors generally do not divulge a great deal of information regarding their sexual activity, case 13 provides one of the few intriguing aspects of how sexual activity is understood to be impacted by medication intake. Case 13 makes a direct connection between his blood pressure medication and his ability to obtain a penile erection. Case 13 tells the interviewer that this is something his mind really thinks about. Where for case 11 not being able to make a sandwich is expressed as a time when his body dys-appears, case 13 offers impotency issues he believes to be linked with his medication as such an embodied experience. This relationship between his medication intake and his sexual activity may also clarify one of the reasons he frequently negotiates with family members about strictly adhering to his medication regimen. In the following extract case 13 also describes his penis as a voluntary actor; that is as a performer. One side effect of his medication apparently impacts his penis, in that “it won’t perform.” Thus, while his family sees the pharmaceuticals as “good,” the stroke survivor sees the medication as also being “bad” for his functional self.

Int: Now, do you feel that your stroke has changed the way you relate sexually?

Par: I feel like them, them ah, high blood pressure pills they give me, affect me.

Int: Okay.

Par: Like that.

Int: In what way?

Par: Um, in the erection part. It a, it'll bring my nature up, I feel like there's too much blood pressure, you know, build it up, it'll, it'll bring it down like that. It won't perform.
Int: Um-hmm.

Par: I have to look at a lot of things that make my mind think about it, really think about it. Other than that, when I take them blood pressure pills? Nuh-uh.

Int: So you think it's more related to the blood pressure pills as opposed to the stroke itself?

Par: Um-hmm.

For most of the stroke survivors presented to this point, medication scheduling often relates to health maintenance as it pertains to such factors as diabetes, high blood pressure, and high cholesterol. Case 24 offers a different perspective. He sees his physical problems related to stroke and age, with medication primarily used to help stall the bodily affects of time. In the extract provided below, while stating that the stroke has impacted his memory and caused left-side weakness, case 24 also discusses the types of medication he takes, explicitly expressing his medication regimen as an attempt to combat the physical limitations he sees resulting primarily from age, rather than resulting from specified co-morbidities. Thus in this extract from case 24’s interview, it is the process of aging that the medicine must combat.

Int: … are due to the stroke like your memory loss or to…

Par: Yeah that's due to the stroke. The age I (clears throat) noticed I have, I have trouble with my hips (clears throat) getting tired. I'm a little overweight and now with the right leg being weaker I find it's putting a strain on my left hip. But it's something I just have to stop what I'm doing, sit down rest a minute. It feels better you know. I can take chondritin and glucosamine and Ibuprofin and stuff and it, I don't have the problems. It's the age stuff is a lot of it but the stroke, the weakness in the left arm and I'm left handed.

Up to this point in the current section cases 8 and 13 have been the participants to distinctly reflect upon the pharmaceutical paradox that medication is needed to help
maintain health, while it can also cause bodily damage. Case 8 is worried about organ failure and case 13 is more concerned about penile dysfunction. Due to ingesting high dosages of medical chemicals, case 27 describes the impact newly prescribed medication has had on his sleeping pattern. Describing himself as a “morning person,” case 27 tells the interviewer that he didn’t feel like getting up this morning, “but it’s a good day.” The interviewer asks case 27 if he didn’t feel like getting up due to fatigue. He answers no. He didn’t feel like getting up due to eating his medication, which seems to have a strong impact on his nightly sleeping activity. He takes the medication to help control his blood pressure, but a side effect of the medication is restlessness, which case 27 indicates is currently causing him some stress. This stress due to a poor sleeping routine is also expressed as negatively impacting his blood pressure. As the following extract shows, while case 27 relies on the medication to maintain his blood pressure, the lack of sleep resulting from the medication stresses him, indicating that the medication has both health benefits and health costs. Although thanking God for the medication, case 27 also wants a good night’s sleep.

Int: So what's the best part of your day now?

Par: (chuckles)

Wife: It's still mornings. Still morning

Par: Well I'm a morning person yeah. Today I didn't feel like getting up but it's a good day.

Int: But today you didn't feel like getting up because you were tired?

Par: No, because I ate my medication and I hadn't slept in three days. I was just uhh, when I got the medication I said oh thank God 'cause now I can get back. Instead it was, I go thank God 'cause I can use a night of sleep. But you’re staying up all the time. You know I get where I'll lay down and I just keep waking up every thirty minutes.
Int: Right.

Par: So you’re not asleep. You’re not getting any rest during that and I'll fall back asleep. I'll have a dream. I look up at the clock and I'll think oh I was dreaming. I got a few hours sleep. Then it's like twenty minutes later (chuckles) that you're not resting.

Int: I know.

Par: Right now a lot of this is physical but the stress isn't helping with the blood pressure.

Even with negative aspects of medication expressed, cases 8, 13 and 27 express the importance of medical adherence, even if the effects of such adherence seem to fluctuate. Case 13 describes his family’s insistence upon his maintaining a medication regimen as helpful for his recovery process. Although complaining about the side effects of their blood pressure medication, cases 8 and 27 advise other stroke survivors to do what the doctor tells them to do. This is probably “smarter” than doing one’s own thing. Case 27 draws this conclusion from recent experiences where when he does things he is “not supposed to,” he gets extremely painful headaches.

The participant states that such headaches can come on at any minute and he does not know what causes them. Before the stroke case 27 “never got headaches.” Now it is not uncommon that he experiences so much pain that “you wanna just rip your head off and throw it in the can.” Thus, when case 27 stands up and attempts to perform some activity there are times he experiences headaches that make his body dys-appear, the presence of which negatively impacts his sense of embodiment to the point that he feels like ripping his head off and throwing it away. Case 27 states that he’s dealing with it, noting that he hasn’t been on his new medication for long. “So maybe it will get better… We got to try right?” These statements made in the below extract taken from case 27’s
interview indicate that things are not better, but since he doesn’t know of any other
reasonable alternative, maintaining his medication regimen seems to be the best chance
he’s got to alleviate the headaches. Case 27 continues to ingest pills, hoping the next one
he swallows will provide the cure.

Int: There's nothing else you'd like to, any advice you'd like to give?

Par: Well just do what the doctor tells you probably be smarter ‘cause I noticed when
I'm getting up and doing things I'm not supposed to do I get to feel the difference
in how I feel. So you, it's like it's, you know in my case it's like I was going to
say hourly, or it might even be minutely, you know? Just any minute I could just
you know, and the minute that it starts running down I don't know what caused it
or whatever. But like I said, I never got headaches. These kinds are like they are
like amazing you know? You wanna just rip your head off and throw it in the
can. I don't care. This is just... but so far I'm dealing with it and you know
hopefully... I haven't been on the medication a long time. The new medication.
So maybe it will get better. Maybe it will come up. I think so. We got to try
right?

Int: Yeah.

Par: I think so.

Case 27 decides he is not one to give others advice about stroke recovery because
he is not “setting an example.” A college graduate, he feels that he should be dealing
with the pain he is experiencing “better” than he currently is. Case 27 states that he tries
not to bother his family, but sometimes he gets frustrated when the kids are playing,
which is generally a “good” activity for kids to do, but perhaps not “good” for someone
experiencing tremendous headaches. The participant offers an even more recent
example, stating that when the interviewer was talking with his caregiver case 27 began
experiencing pain in various “spots” in his head. A medical expert informed him this
would occur because his nerves are getting “more sensitive.” Case 27 then blames his
nerves, stating that they need to “chill out because they too sensitive and the headaches
are amazing. They really are.” Although not experiencing much positive result from his medication, case 27 ultimately decides he has improved, providing evidence of this by describing his mopping of the floor a day prior.

Yet in describing this activity, case 27 indicates he thought the mopping was going to “kill” him. This is described as bad, because after all it is a “small place.” The floor needs swept twice a day, but he’s not up to doing that yet. Through it all, case 27 concludes, “just do what your doctor says man.” When asked if that’s it, the stroke survivor answers, “yeah, I think so. Wouldn’t you?” As expressed in the next extract, even with no substantial gain from doing so, case 27 sees medical adherence as his only opportunity for physical improvement.

Int: Any advice you'd like to give to another vet about how you're handling things? How you're feeling right now?

Par: No. Now is not a good time for that. I'm handling them you know but I know I don't think I'm setting an example okay? And I majored in college in school in college okay so I should be dealing with this better as far as you know when I hurt is when I'm alone here. That when family is here and that I try to not bother them. But I hear ‘em talking and the kids playing and that's good but when I'm alone it, when you were over here first talking to her and that I started feeling all the little physical things. The pain that and like if you could feel it in all the spots where it was and Nancy said that this is gonna happen ‘cause what it does it the nerves get more sensitive so you're gonna feel it now. Your head will, my head nerves need to chill out because they too sensitive (chuckles) and the headaches are amazing. They really are.

Int: Yeah.

Par: I just, the pain pills don't really work. When I'm calm and not getting excited or getting working around here.

Int: You're better?

Par: Actually yeah. Like I mopped the floor yesterday and I thought it was going to kill me (chuckles) you know and that's bad. I mean it's a small place. I actually hate the tile. I want carpet. It’s cold on my feet, it looks great, but there's hair
everyday. It's got to be swept everyday, sometimes twice a day. But the thing, and I'm not up to twice a day (chuckles). Just do what your doctor says man.

Int: That's it?

Par: Yeah I think so. Wouldn't you?

Initially, case 21’s extract describes his medication maintenance as many others do; simply part of one’s routine everyday practices, relating medication intake as a practical means to control the effects of diabetes:

Par: Well when I wake up I take my Diabetes medications. Later I have breakfast and during that time I turn on the TV to watch the news to see what is happening and from there I sit to watch a little television, organize my day & the things I need to do, because, although I do not work outside, I have to check the telephone bill because sometimes they put phone calls that you did not make.

At a later point in his narrative, however, case 21 describes a feeling of abandonment regarding his experiences with his medical provider. As a participant in a medical study, case 21 took a specified medication, Avandia, as well as also taking morphine, and insulin. Informing medical personnel that he was concerned about his weight gain and fluid retention, nothing was done to assist in alleviating these concerns. All medical personnel, specifically his attendant Lorraine, communicated to case 21 was, “hello,” “how do you feel,” and “go get your medications.”

Although traveling to the hospital, making his appointments, case 21 believed that medical personnel were “not taking care of me like a person should be taken care of in a study.” That is, medical experts were not providing adequate medical monitoring. Case 21 then had a stroke. After these experiences, case 21 saw on television that ingesting Avandia with other medications may lead to dangerous levels of fluid retention. Through the details of his experiences as a subject in an experimental drug study, case 21 describes this type of medication schedule as “inhumane.” He states that he was treated
very poorly, not given individual care, and not taken care of as a person should be. This extract provides a poignant example of some of the dangers to medical adherence.

Par: I feel abandoned by the VA hospital. I think they made a mistake because they keep calling me to ask me about a study I was in. And the first thing the doctor said was that the study had abandoned me because the medications they were giving me, which I am no longer taking, ehh I had already told them I gained a lot of weight quickly. You see how big my belly is, I had a waist size of 38 and now I am a 42 and this happened during this year in a matter of months. When I called and explained this to them, they did not say anything. When I would go to the hospital for my scheduled appointments for the study with the Avandia, Morphine and insulin they were giving me, Lorraine, who was attending me, would say "How are you?" And "Hello. I saw your face," and that's it. "How do you feel?" And “here, go get your medications.” They would not check my weight regularly. They did not check my blood pressure. In other words, I would go to the appointment but they were not taking care of me like a person should be taken care of in a study. You know the monitoring that they were giving me was, like they say, almost "null," very little, they treated me poorly. Well, then I had a stroke, something I did not have, because I was retaining liquids. My people kept telling me that I am getting fatter and fatter and later watching the television I saw that Avandia mixed with other medications may cause some people to retain fluids and that's very dangerous.

Case 21’s extract, similar to those of cases 13 and 27, offers a glimpse into how one’s sense of embodiment may become problematic due to the ingestion of certain prescribed medication. The last example included in this section regarding the effects of medication maintenance as it relates to self-care, case 9, presents an extensively detailed account of how pharmaceutical intake can directly influence feelings of social stigma and personal abnormality. Case 9, a 52-year-old former construction engineer, retains a sense of self that remains closely grounded in paid work. Divorced and currently living with his fiancé, his age and current living arrangement may influence case 9’s position regarding his current lack of gainful employment. At first, however, case 9 does not focus on the impact his medication has on employment opportunities, but rather focuses on losing vision in his right eye in 1994, stating that “since ’94, you could consider I lost
my life.” Case 9 doubts he will ever be able to go back to doing what he loves; high-rise construction. In that life-world, case 9 “was in charge of everything that happened.”

Int: You're sayin' like compared to before you feel like your life is shot. Is that what you mean?

Par: You know a damn thing I ever really do, is because of the medication. This building (showing picture), forty stor, forty-three story Barnett Center in Jacksonville. That's me, and that's my son that I can't see. But, I'm so smart, uh, 3 or 4 uh people in Jacksonville were bidding' on me, cause I'm the only one that had high-rise, high-speed construction of this nature. If you ever go to Jacksonville, Florida, that buildin', I signed every piece of inspection, concrete, shoring. I was in charge, of everything that happened. I went sixty feet below Bay Street to do calculations on the foundation.

Int: So do you think about that now?

Par: Oh, yeah.

Int: I mean, are some days worse than others when you're thinking about what you did before compared to what you can do now?

Par: When you're numb so much, you got the s-smarts, and yet I'm a risk. First off, I lost my right eye, vision, and ah, September 4, 1994. I have no depth perception, and uh, I'm not gonna step off a buildin'. Since '94, you could consider I lost my life.

Int: Are you talking about from your, when you lost your vision?

Par: Yes. And since then I've had doctors pump medications in me. I did try any; they try to give me everything. This is just like the doctor Zhan again. I said no. The pills they put me on last month and I thought well they ain't gonna work.

The interviewer asks case 9 if when stating he lost his life, he’s referring to his loss of right-side vision. Case 9 answers “yes,” but then also discusses life after that specific health event, stating “since then I’ve had doctors pump medications in me.” Case 9 states further that the new medications he is prescribed “ain’t gonna work.” In the next extract from case 9’s narrative the interviewer attempts to have the participant distinguish between the impact having his vision impaired some years ago has had on his life from
the impact the stroke has had. Case 9 says that the stroke has limited his ability to functionally perform minor things, but then returns to the impact the medications have had on his life. As case 9 informs, “there’s a lot of people out there with one eye.”

Int: Okay. You kind of were talking about your life before you had your stroke, when you were talking about being an iron worker and engineering tech, that it's a lot different now. But, is it, more because of the stroke or because of losing your vision you feel like your life's different?

Par: Well my health has stopped me from doin' what I loved.

Int: But is it more from the stroke? I mean, what, what kind of things can't you do now, I mean what kind of things could you do before you had the stroke as to what you do now?

Par: Minor things I'm not, I don't have the capacity.

Int: It's minor things?

Par: Yeah.

Int: Like?

Par: And I'm sure it's the medication. There's a lot of people out there with one eye.

While the participant initially states his life was lost when his right eye vision was impaired, he then shifts his comments, concluding that there are a lot of people with one eye. In fact he adds, “there are a billion people out there that don’t have one eye, but they’re still out there. They’re still in their occupation.” At this point the interviewer asks if the feeling that his life is lost more a result from medications he is currently taking than it is to losing right-side vision:

Int: So you think it's more from the medication that you have to take ‘cause of the, to prevent the stroke?

Par: Yeah. OD, over amount of medications has stopped my life. Now, there a billion people out there that don't have one eye.

Int: Right.
But, they're still out there, they're still in their occupation.

Right. Okay. So, you're saying it's more from the stroke medication, you think?

Overmedicated.

Well, how do you feel now, like, if you'd give me an example of how you feel now, being overmedicated and from before not being overmedicated. What's it feel like to be overmedicated? Does it make you...

It stops you from doing everything.

Case 9 informs the interviewer that being overmedicated stops you from doing everything. The interviewer then asks the participant to provide more concrete reasons why this is the case. Case 9 informs her that he has worked outside his whole life, and now due to the medication it is difficult for him to be outside more than 10 minutes without “sweating like a madman.” When this happens he must go inside and sit by his fan or else he begins vomiting. The participant adds that he has never tried working outside while not being under the influence of medication because he’s afraid not taking his medication will result in another serious health event. But he never had these feelings of intense nausea and overheating prior to taking his prescribed drugs:

But why? I mean, what effect does the medication have that stops you. Is it, for example, does it make you tired or just groggy?

No, it's like, if I want to go outside, see I was a mechanic all my life, too. And I got out of that in the 70's when I went in the Army, but the old tractor I got with the cover on it, my old truck. If I'm outside and it's hot more than 10, 15 minutes, I start sweatin' like a madman.

Then, I have to get in here and I'll sit in front of my fan on three while it will just go around.

Right.
Par: Otherwise it would make me throw up.

Int: In the heat?

Par: And, uh, without the medication, well, I haven't tried doin' it without the medication because I don't want to take a chance on a stroke, heart attack or seizure.

Int: Right:

Par: But, I'll get out there, and when I get hot, within 20 minutes I'll be so hot I'll just start throwin' up.

Int: Hmm.

Par: And I ain't never had that.

At this point in the discussion the interviewer asks case 9 if the functional limitations related to his medication intake influence how he feels about himself. The participant answers, “of course. My whole life is wiped out.” Case 9 then reflects on an old employment activity he did while on different heart medication. Once that employer “went under,” case 9 had to seek other employment, but as the participant states, he is “a risk.” Once he lost that job due to the company closing, the only job he could land was at a lawn mower and small engine repair shop, where the pay was not adequate for the labor time he contributed. Case 9 then goes back to discussing how once he got on the medication he couldn’t do it because he’d just start sweating “like somebody was running a quarter-mile race.”

Int: Never had that before the medication? So do you feel, I mean, do you feel different about yourself now cause of how you're limited with, 'cause the medication you're limited?

Par: Of course. My, my whole life is wiped out. And, without the medication? When I came up here from Middleburg, I was on um, a Chlondine, one other heart pill, and two, uh, Amytripoline, 200 mg at night. And I, I was workin' for uh, Wood Hopkins pile drivin' company. I don't know how long, how many months. And
then they went under and another company was buyin' it. But, still, I'm a risk. And after Wood Hopkins went under I said "Hell with 'em". (coughs) And, uh

Int: So was that your last job?

Par: Basically (sniffs). Cause I went to out to a small engine and mower shop, and worked a couple of months, I guess, or whatever. My, I could make that money in a day. So I just got out of it. But, once they got me wound up on that medication, I just couldn't do it. I'd sweat, yeah, like somebody was runnin' a quarter mile race.

The interviewer shifts the talk from the physical impact case 9 relates to medication intake to the psychological impact, thus taking a classic Cartesian dualistic position.

Case 9 does not seem to be troubled by this other-structured interpretive framework. He informs her that he feels shut down, but adds that he’s not going to commit suicide. He offers one way he could, however, by taking a large amount of his medication. He could do this, but he’s a “survivor,” and “would never try to take my life.” While he wouldn’t physically end his life, he states that his life indeed is “gone.” The interviewer then asks what he means by saying his life is gone. His answer is that it means that no one will hire him. As the below extract illustrates, the reason for this is the medication, not his self. As a former engineering technician case 9 knows he isn’t an “idiot.” His work was his life, and he’d love to wake up at 3am and begin his labor. The problem is he wouldn’t pass the urine test.

Int: Right. Well, like, okay, other than, you know, the physical changes you're feeling and about sweating and, and all that. How do you feel, like, psychologically, like do you feel, do you get…

Par: First off, shutted down. I'm not gonna kill myself. Believe me, I got enough medication, I could take five of all of 'em, and I could ruin my life. But I'm a survivor, and, uh, I would never try to take my life.

Int: Well, I guess, I guess I wasn't.

Par: My life's gone.
Int: Right

Par: But I still wouldn't take it.

Int: But um, okay, but when you, when you say your life's gone do you, what do you really mean by that, when you say that? Are you just, are you talking about…

Par: I can't get hired by nobody.

Int: So, but I mean, are you talking about work? Or are you talking about, when you say your life's gone do you tie it to work?

Par: Medication. I know a lot of people, and if I'm that damn smart, they would put me, senior, as senior engineering tech over that building, 40 story buildin'. They're not gonna put an idiot in there.

Int: Yeah.

Par: And the knowledge of high-speed, high-rise construction was my life.

Int: That was your life?

Par: I got my brother in it, like 17 years ago. And, I mean, things have changed, but he's here, uh, at Lake City, Orlando and all that. Tampa. He's the area manager over all that. I would love to wake up at 3 o'clock in the morning and go to work, but when you got to take a urine test, hah! How you like me now, boys? Shit. I hope it don't give him that one, get transfusion. It's like, hey, medication I'm on? I can't give blood. That boy, howdy, get my, let's do the transfusion, get about one bag of mine and put it in you. You'll wake up, might be a week or so, but, it, when you take a urine test it's scary.

Although indicating that medication has ended his life, case 9’s hope for the future still centers on new pharmaceuticals. He states that “maybe in five years they’ll have a medication out that would work on me and I can go out there and be human.” This statement defines his self as something that is not currently human. For case 9 being human seems to be intimately linked with being employed. His current medication, then, is preventing him from being human. Even with this understanding of medication
effects, case 9’s hope for once again being human relies upon medical science. As his television informs him, medical science is coming up with new formulas every day.

Par: 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 every day. They tell you on that television right there, but I, I uh,

Case 9 continues describing his hope for the future: a wonder drug. As long as Jesus is with him no one is going to harm case 9. With the aid of Jesus and medical experts, perhaps one day he will only have to take one pill that will maintain his health state and enable him to go fishing, be happy, mow the lawn and go swimming. Case 9 informs the interviewer that his hope for functional ability is oriented around “simple things.” Maybe one day medical experts will produce a pill that will stop the physical pain, yet not “kill your brain.” Case 9 then interrelates his family situation dealing with his estranged ex-wife and 13-year-old son with his religious perspective and the pill they may create next year.

Another activity, selling one’s own prescribed medication is indicated as an employment possibility that case 9 has decided he won’t do. He informs that there are “nuts out there that are actin' crazy to get pills,” and that supplying this market demand could be “your backup income.” But due to divine retribution case 9 does not oblige the “nuts”: “You have to pay for your sins. Not mine, not the dog's or anybody else. When you die, all God's gonna judge you on is your actions. And, boy, there's a bunch of 'em that, huh, gonna pay Hell.” While this is mentioned by case 9, the interviewer does not question if the participant has ever seriously considered that activity as an income source. Considering that some of the stroke survivors take 30 different pills a day and many of them are no longer employed, indicating that they currently have annual incomes under
$15,000, it may be that those less certain of eternal damnation may be more inclined to share certain parts of their pharmaceutical kitty to those willing to pay for it.

The interviewer does ask if it is not being able to do simple things like mowing the lawn or not being employed that case 9 most desires doing again. Case 9 answers he’d love to go back doing iron work, but it seems that if he can’t go outside and do simple things like fish and swim, then having the ability to adequately function as an industrial laborer is even less practical for him to expect. But who knows? Maybe a pill will be available that will allow case 9 to do everything he wishes he could. Perhaps this perpetual hope for the perfect pill, coupled with his faith in God, is what ensures case 9 that he will never kill himself.

Par: Like I told Dad, as long as you're with me, Jesus is there, and He ain't gonna let nobody hurt you. And, uh, you'd better believe it. But, uh, no, like I said, they may come out with a pill that I can take one a day, eliminate the blood pressures and everything, and go out fishin'. Happy go lucky. Ride a lawn mower. Mow the yard. Simple things. And you don't know, they might come up two years later with a pill that would stop you from hurtin', but won't kill your brain, and uh, tha-that's what I'm lookin' at. See, I got a 13-year-old son. His mother's a pill, but one day everything may change. When he's 18, if he wants to see his Daddy, I will go get him. And he ain't that far away, and uh, I may not, you got them nuts out there that [who] are actin' crazy to get pills or some, your backup income. You have to pay for your sins. Not mine, not the dog's or anybody else. When you die, all God's gonna judge you on is your actions. And, boy, there's a bunch of 'em that, huh, gonna pay Hell. Well, I, no, that's what like, really, they have a pill next year.

Int: Right.

Par: That would make me eligible to do outside things and have fun in the yard or go swimmin' or anything. When there ain't nothin' close enough make me want to kill myself.

Int: So, it's not just, I mean, it's not, you say you mostly miss work, but it's not just work, it's also, you just naming all this simple stuff you used to do. Everyday things.

Par: I, you, you'd have heard all this dog and I'd love to be able to go back doin' iron work. Well, see, I was superintendent. I love ironwork. And, uh, but no, you got
any of those crazy people you'd better stop seein' 'em. Like I said, a year, two years, five years, ten years. They may have the formula to let me and millions of people go outside.

Int:   Right.

Par:   And, uh, if they don't, they don't. I ain't gonna kill my damn self. It may, it be occasion of ten years, and they [par is discussing finding a cure for his problem] maybe it's Bingo. And I have too much desire to live. And, but no, I'm no, I ain't close, I don't even think about that kind of stuff. I don't know if I just messed you up, but no, that's how I feel.

The interviewer then asks case 9 what advice he would give another person going through a similar experience as he is. Case 9’s advice would be to find out what medication the person was on, and if it is “bringing you down,” switch to a different drug, because there are a lot out there. Case 9 adds that a person should not get to the point where they have a stroke. The way to do this is dietary control. Shifting back to his medication, case 9 says he knows what pain pills can do, but he doesn’t know anything about heart medication. So he wouldn’t be able to share his medication with another person because it might kill them. After this lengthy, complex narrative regarding medication intake, the interviewer asks case 9 if medication is his biggest concern. The participant answers affirmatively saying, “there ain’t no doubt in my mind.” Still, even with these effects, case 9 is not giving up. People who give up are “crazy.”

The participant then discusses people like truck drivers, superintendents, and helpers who are probably on medication but “it’s not affecting their day job.” He also assures the interviewer that he wouldn’t share any of his medications because it could kill someone else, particularly his heart medication which case 9 knows much less about than he does pain pills. The interviewer laughs, telling him “good.” That is, it is good that
case 9 does not distribute pharmaceuticals. It seems collaboratively agreed upon by interviewer and participant that the only people who should distribute drugs are state certified medical experts.

Int: If you had to, just say that you met another vet, say that just had a stroke just recently and you were going to give him some advice, what kind of advice do you think you would give them? What could they expect?

Par: I would ask them, like, "what kind of medication are you on?" And you might have to go to a different doctor, or go to your doctor and ask for a different medication because this one's bringing you down. And I'll tell them there's too many medications out there for blood pressure.

Int: Right.

Par: You know, really kind of worry about it, and, and you shouldn't bring yourself up to the point that you have strokes. You gotta back off on the, ah, sugars and, uh, starches, change your menu.

Int: Um-hmm.

Par: And just try that. But I ain't gonna give 'em none of my stuff.

Int: (laughs) Good.

Par: Yeah, good eatin' here. See, that's the one thing I really don't know about, is, uh, medications for your hearts. And, uh, now see, mine might kill him, and, uh, I know what you can do with the pain pills and stuff like that, but I know nothin' about heart medicine.

Int: You think that's like the biggest issue for you, is, has been your medication?

Par: Yeah. There ain't no doubt in my mind. But, uh, just because you have strokes, or seizures, or anything like that, you don't give up. I mean, ah, Hell, that's the worst thing a man can do. And, no, if you give up and think that you're gonna be dead anyway for somethin' like that, you're being one of those crazy people I'm talkin' about. But, you got truck drivers, probably drivers of, head of them trains out there runnin' a hundred miles an hour. Superintendents. Helpers. They're probably on medication. But it's not affectin' their day job.

In the final extract included in the current section, case 9 expresses his knowledge of Dilantin, stating he is on a new pill because Dilantin shut him down to where had no
But case 9, being a survivor, is not going to quit, because if “you quit they win.”

Par: But, uh, no, if I met somebody an, and he told me he had a seizure or stroke or something like that, Dilantin was the biggest thing for seizures.

Int: Dilantin?

Par: Yeah, years and years and years ago.

Int: So, are you using Dilantin now, or something else?

Par: No, they gave me a new pill.

Int: A new drug? It's not Dilantin?

Par: No. Dilantin shut me down. I couldn't eat, I had no desire to eat and, uh, Hell I'd go, I went a week without eatin’ . . . . If you quit, they win. That's, that's always been my thing. You quit, they're gonna win. Now where's the fight in you?

**Medical Knowledge and Bodily Discipline**

Peter Conrad and Joseph Schneider (1980) outline the growth of medical expertise throughout the 20th century, noting that physicians often see their professional values as the values that laypeople should implement in conducting their everyday embodied activities. This form of knowledge transference is illustrated in the two sections regarding self-care practices presented thus far; namely via dietary regimen and medication maintenance. Time and again the advice the stroke survivors offer to others is to eat better, take your medication, and always listen to your doctor. The term therapeutic state is frequently used in describing the various community-based programs such as Alcoholics Anonymous and drug treatment facilities that organize and discipline bodies according to a religious corporate-medical discourse. Those recovering from stroke at home often orient their selves to everyday life in accordance with medical knowledge by “doing what they’re told,” to do by medical experts. With this said, the
stroke survivors also implement other forms of knowledge, such as religious ideology, when providing meaning to everyday life, just as Alcoholics Anonymous does. The interpersonal context of the home, mass media, as well as biographical information such as past employment activities, also factor into the ways in which stroke survivors reflect upon their current lived experiences as well as the care and nourishment of their self.

At this point in the analysis of everyday self-care practices of relatively high functioning stroke survivors certain patterns have emerged. Arthur Frank (1991, p. 48) suggested that discourses “imply cognitive mappings of the body’s possibilities and limitations, which bodies experience as already there for their self-understanding.” Medical discourse is explicitly expressed by many of the stroke survivors included in the current sample when reflecting upon the routine everyday activities of eating and medication maintenance. Although neither the FIM nor the FAI contains an item regarding medication intake, as illustrated in this section, such an activity is often related to the adequacy of self-care. In fact, many of the participants state medication maintenance to be one of the most important practices one must ensure he is able to perform.

In providing advice to other survivors, these participants commonly indicate that the best thing to do in the recovery process is to listen to the doctor and take their medication. This advice illustrates the normative parameter of how the body should understand itself. Yet, as Frank (1991) asserts, such a parameter is a fluid resource that allows for self-variation and self-improvisation of dietary and pharmaceutical ingestion practices. Some participants radically alter their diet (dietary will) while others do not. Some participants ingest medication without questioning its effectiveness or possible side
effects while others, like case 9, seem to continually ponder the pharmaceutical paradox of needing the medication to prevent a serious health event while experiencing personal problems believed to be a result from medication intake. While medical discourse and the institution of the hospital clinic help to create a medical gaze that is alert everywhere, ultimately bodies emerge from other bodies. That is, the body is a material object. This corporeality of bodies represents the physiological dimension of embodiment. Within space and time one’s body has real limits. These physical limits of one’s body are explored in greater detail in the next chapter.
CHAPTER 6
NEGOTIATING CORPOREALITY

David Wasserman (2001) noted that while many standard motor functional activities have intrinsic value it is difficult to determine how the loss of a given motor-functional activity impacts one’s sense of overall well-being. In order to gain a sense of the relationship a given motor activity has to one’s overall sense of wellness one must understand the person’s ongoing concerns. Carol J. Gill (2001) suggested how such an understanding may be accomplished; stating that in order for research to be useful the perspectives of those who are experiencing the disability being studied must be included rather than excluded.

Instead of only using FIM and FAI scores in determining how stroke survivors physically manage daily motor activities, this chapter presents an in-depth look into the participant’s reflections on daily life, in particular as they relate to getting up, getting ready (that is, going to the bathroom for bladder and bowel relief, shaving, and showering) and getting dressed. This bodily preparation is a daily routine that is often altered after stroke. A scaled rating may provide a general sense of the level of assistance the stroke survivor needs in doing one or more of these activities, but such a rating does not offer insight into how this physical change impacts one’s sense of self or one’s sense of being-in-the-world. Narrative extracts from interviews conducted with those who are at home after having had a stroke offer the missing piece in understanding how these participants negotiate and manage their bodies within the home environment.
Bathroom and Dressing Work

The FIM and how it examines self-care was briefly described at the start of the previous chapter. It was mentioned that eating, grooming, bathing, dressing, and toileting are activities labeled as self-care tasks by the FIM. Grooming is defined by the FIM as including “oral care, hair grooming, washing hands and face, and either shaving or applying makeup.” The activity of toileting includes “maintaining perineal hygiene and adjusting clothing before and after toilet or bed pan use.” It is such self-care activity that the first section included in this chapter is concerned with.

Medication maintenance was outlined in extensive detail as an example of a self-care activity expressed as quite important in the lived experiences of these stroke survivors that is not reflected in commonly implemented clinical measures such as the FIM and FAI. This chapter, and Chapter 7 which pertains specifically to the meaning and importance of walking in everyday lived experience, deal specifically with how these stroke survivors reflect upon their physiological concerns, further clarifying embodied consciousness, which according to Frank (p.51) “is always a body conscious of itself.” Using the concept of bodily dys-appearance as suggested in the work of Drew Leder (1990), for some of these stroke survivors, particularly in the early stages of their recovery, embodied consciousness arises when one first faces problems in routine self-care activities such as going to the bathroom and dressing. These activities, which were taken for granted practices in the past, now become work that requires assistance from other bodies, or from technological devices. For some high functioning stroke survivors, such as case 29, dressing and bathroom work does not become problematic. The unproblematic nature of such practices are indicated by his FIM ratings of complete independence for bathing transference, grooming, and dressing upper and lower body.
As the stroke survivor indicates in the following extract, like many, case 29 gets up, showers, eats breakfast and takes the medication he is prescribed.

Par: I get up in the morning. I take a shower, then I eat some breakfast take my medications that they order me. Then the rest of the day I been basically running around. Sometimes I do physical, you know, I do exercise.

For others, like case 1, getting up presents this stroke survivor with problematic aspects of corporeality. Although rated as completely independent in all self-care tasks included in the FIM, in the below extract case 1 illustrates how he uses his morning routine as a resource in evaluating his physiological status. Getting up and getting some “early air” is expressed as therapeutic, in that it keeps case 1’s “limbs movin’.” In discussing his bathroom routine, case 1 informs the interviewer that his urination practices seem routine, but his bowels are working slowly. This discussion represents a corporeal shift from a once predictable body to one of unpredictability. In the extract provided, this level of unpredictability is related to a change in appetite. Such unpredictability is not illustrated through assessing functional ability according to the stroke survivor’s FIM score.

Par: Get up in the morning, early in the mornin' and you know, walk to the rest room and wash my face, brush my teeth and things, and get up and get some of this early air and gotta move enough to keep my limbs movin'. It seemed like to me they slowly working. Now, uh, I notice here that I have to go to the bathroom real regular on the urinating. Now, it's slow on bowel because it looked like I want the food but when I get it, uh…

Case 23 is also rated as completely independent in self-care tasks. In the extract that follows, the stroke survivor tells the interviewer that his family does not “have to do nothing for me.” He then says that if he had to use a bedpan to help with bladder and bowel management then things would be different. Such issues are seen by case 23 as personal. He wants to be left alone to look after himself. Not needing such things as a
bedpan is used by the participant to illustrate that he is still independent and is fortunate in comparison to others who have had a stroke.

Par: They don't have to do nothing for me. If I was using a bed pan or anything like that it would make a difference.

Int: Right

Par: Because I'm self conscious about these-things-

Int: -things-

Par: -you know which I could consider personal.

Int: Exactly.

Par: Other than that they don't have to do nothing for me. Leave it alone.

Int: Right.

Par: Leave it alone. Leave me alone. I take care of me.

Int: Yeah right.

Par: I'll look after me because if you don't look after yourself who is gonna look out for you?

On the other hand, case 17, who also is rated as completely independent in self-care tasks, discusses his artificial urethra and how one must allow others to help without getting embarrassed. This information seems to be quite different from the position taken by case 23. Case 23 finds toileting issues a private matter, stating that he wants people to leave him alone. He wants people to leave “it” alone. Case 23 expresses the understanding that the only person he can, and should, rely on is himself. Contrary to this position is the extract provided from case 17’s narrative as he reflects on body issues he may be dealing with in the future. He states that even if the person providing aid in self-care is not a spouse, such as a visiting nurse, one should “just give yourself over to
her and show a nice attitude toward her.” Case 17 informs the interviewer that these nurses “want to do for you but you won’t let them.” Such a situation is seen as describing a person with a “very, very poor attitude.” The end result is that necessary self-care activities fail to be accomplished due to the individual’s lack of cooperation with care providers.

Par: The difficulties that they're going to have is first of all, because I've been around people who've had stroke, is that they become incontinent. The fact that they were able to do certain things for themselves and they no longer can do it. Another person is willing to do it and is able to do it, let them do it without you feeling embarrassed. They may have to change your diapers. They may have to wash your body entirely and parts of your body that you probably would hold in secret other than to your wife. The fact that your wife, she may be ill herself. I mean she could be very well down and not able to wait on you. Then you have other nurses coming in. And the fact that your wife is not able to, that nurse knows what's she's doing. She's been trained to do it. Just give yourself over to her and show even, a nice attitude toward her. I say, because nurses sometime, when they go out, especially those who will visit patients, they run into people with very, very poor attitudes and you can imagine how they feel. They want to do for you but you won't let them. And when you don't let them they're not going to force you because you're the patient.

In describing getting up in the morning, case 17 states that not much has changed. The only difference he is currently experiencing in his daily routine is the labor required in bed transference due to his left leg “buckling.” While being able to cook on his own and doing pretty much what he wants to do, he must negotiate with his embodied self when initially getting out of bed. That is, case 17 weighs the urgency of relieving his bladder with the possibility that if he gets up too fast he may fall due to his left leg giving way. As case 17 states, he is “constantly aware” of the unpredictability of his left leg.

Int: Let's start with when you get up in the morning. What is that like?

Par: Um, my normalcy is normal and it's nothing, nothing has changed except that I realize that I cannot get up too quick unless, first sometimes I sit on the side of the bed before I move. Depending upon the urgency of going to the bathroom, because I am wearing um, a artificial urethra, which is, a AMS sphincter 800,
it's called. And this causes me to, maybe rush getting out of the bed sometimes, but mostly if I rush too fast getting out of the bed, I have a tendency to uh, my left leg will buckle under me and I might fall and I'm constantly aware of that so consequently once I get up and start walking around I have no difficulty. I cook my own breakfast and I move around, do what I basically want to do.

While case 23 comments that he prefers to do things, such as bathroom work, on his own, case 18, a participant categorized as moderately independent using one month overall FIM score, rated a 3 (moderate assistance, with stroke survivor performing 50% to 74% of the task) on grooming, toileting, and dressing both upper and lower body, and rated a 2 (maximal assistance, with stroke survivor performing 25% to 49% of the task) on bathing, seems to adopt a position more similar to case 17 in that he gives his self over to his wife and son without expressing feelings of resentment or embarrassment. When asked if he feels frustrated by not being able to do things he used to be able to do on his own, case 18 says that he feels “a lot better. They help me more.” While case 23 does not desire family assistance, the family assistance case 18 receives is described in the following extract as a source of self-pleasure. Thus, for some stroke survivors the need for physical assistance in bathroom work may be described as an example of how one has lost a sense of independence, and for others it may be described as a source of family bonding and expression of interpersonal care that is pleasing for the stroke survivor.

Int: Do you feel more frustrated with things than you did before?
Par: On the contrary.

Int: On the contrary?
Par: I feel a lot better. They help me more. When my wife is not here, he takes me to the bathroom.

Int: He helps you?
Par: Like how he takes me and then I clean myself.
Int: Clearly. He helps you.

Par: The oldest one.

Int: The oldest one.

Par: He is only eleven years old.

The types of activities stroke survivors need assistance with also varies. For some, they need assistance getting to the restroom, but can manage to dress themselves. For others, like case 3, whose FIM score indicates the only assistance he requires is the use of a shower bar when bathing, indicates that he continues to do bathroom work by himself, and manages to check his own blood sugar, but when it comes to dressing, the stroke survivor often relies upon his wife to assist. Case 3 discusses running to the bathroom in the morning, informing the interviewer that “when you get old you gotta go to the bathroom now.” For case 17, the urgency for urination was linked with his artificial urethra. Others do not link morning bladder activity with a specific cause. Others like case 3 in the following extract, link it directly to age.

Int: What's it like when you get up in the morning?

Par: I run to the bathroom, ha ha, I don't run, but I get there as soon as I can. It's just that when you get old you gotta go to the bathroom now.

Int: Uh-huh. So you get up by yourself and-

Par: Oh, yeah-

Int: and go to the bathroom.

Par: Yeah.

Int: Anything else?

Par: I usually come on in check my blood sugar. Stuff like that.
When asked if there are other things his wife helps him with in the daytime, case 3 states that his wife is constantly helping him. He uses an example from only a few minutes prior to the conversation as an illustration of such constant care. Case 3’s wife reminds him that he should get ready because the interviewer is expected to arrive any moment. Case 3 then asks his wife to get him some clothing. She does so, putting shorts on the stroke survivor. While this sort of assistance is said to go on constantly, it does not seem to be a major daily concern, nor is it discussed when performing the FIM rating. That is, the stroke survivor thinks he could dress himself if absolutely necessary, but with his wife nearby does not feel the need or desire to do so. His wife is accustomed to working in the home, doing laundry, washing dishes and preparing all the meals. The fact that she now must do this for her husband because he is no longer able to physically accomplish such activities appears to be of little concern. The fact that his wife must assist with “inside work” is not problematic since this is what she has done throughout their adult lives. As the following extract illustrates, now, she just does a “little more” than she had prior to case 3 having a stroke.

Int: Were there any other things that she does during the daytime to help you out?

Par: Constantly. Constantly doin' somethin' that.. are you ready to go she says? You know it's about time for that young fella to get here. I says, yeah. I said you'd better get my pants. Either the short ones or the long ones, either one. She goes in there and gets shorts. Puts 'em on me. So I say it's somethin' goin' on constantly, she's doin'.

Case 3 may not be overly concerned with the assistance he receives when dressing, but for case 30, a person rated as completely independent in all FIM motor tasks one month after his stroke, the need for such assistance is his “biggest fear.” Case 30 describes his initial return home when his wife had to “do just about everything for me
and help me put my shirt on and everything.” Case 30 has worked at putting his own shirt on and now does not require assistance from his wife. Case 30’s biggest fear is having to continually depend on others to help with such mundane tasks as putting on a shirt. While some of the stroke survivors, like case 18, seem to accept and even enjoy such assistance, others, like case 23, work hard to perform such tasks independently. Case 3 relates age to some of his physiological changes, but as expressed in the extract below, for case 30 age doesn’t matter, at least as long as he can perform the functional activities of thinking, writing, and walking.

Par: Well for awhile she had to do just about everything for me and help me put my shirt on and everything. But now I worked it in to where I could, where I could do it myself and then she don't have to. That was my biggest fear. Havin' to depend on somebody to do something for me you know that I thought to myself that I ought to be able to do myself, you know?

Int: Um-hmm.

Par: That's, that's a fear that I've had. I said somethin' to somebody the other day that uh, I don't care how old I get as long as I can think, write and walk right. I want to walk on my own and think on my own. And I don't care how good. If I get to be 100, okay.

Case 2, a participant categorized as moderately independent in overall FIM score at one month after discharge from the hospital, rated a 4 (minimal contact assistance, with the stroke survivor performing 75% or more of the task) in grooming activities and dressing his lower body, and rated a 5 (requires supervision or set-up) on bathing, informs the interviewer that there are times he wants to do something. The interviewer asks case 2 to provide an example of something he wants to do. The participant uses the desire to put on socks and shoes as an illustration. As discussed in the following extract, not being able to put on his own socks and shoes makes case 2 “feel bad,” but he informs that these changes are “natural.” Case 2 states that he must adapt to these changes, for as
he tells the interviewer, “it is not the same to be well as to be sick.” As provided by case 2’s example, well people can dress themselves; sick people cannot. As a well person, case 2 would drive to the city and take walks. Now as a sick person, he requires assistance in mundane tasks such as putting on socks and shoes. These bodily changes are used to illustrate the difference between well and sick bodies.

As case 2 informs, due to his loss of functional ability, his happiness has ended. Rather than being a benefit to his wife, case 2 now sees his self as a “bother.” Case 17 states that one must accept the need for interpersonal assistance and give one’s self over. Doing so makes case 2 feel “uncomfortable.” Feeling bad about his body’s loss of functioning, case 2 believes he has little choice but to “be satisfied with God.” With his physical, material experiences becoming increasingly problematic, case 2 attempts to find personal solace in a metaphysical world.

Par: At times I want to do something.
Int: Like what?
Par: I want to put my socks on and shoes and I have to call her so she can help me.
Int: Yes, and do you get frustrated? How do you feel when?
Par: Well you feel bad but you have to adapt. It is just something natural. Before no. I would take the car and I would walk to the city.
Int: Umm, okay, now lets talk about how you feel, how you feel not how... not about your body but about your thoughts and feelings regarding what has happened with the stroke?
Par: At the moment, I have to think because it is not the same to be well as to be sick.
Int: But do you feel that your... your thoughts regarding yourself as a person have changed?
Par: They changed.
Int:   How?
Par:   One's happiness finishes.
Int:   Yes?
Par:   Yes, it finishes, what good is someone who is sitting in a chair? It is a bother.
For a companion how do you live?
Int:   Do you feel you are a bother to your wife?
Par:   Well, yes I do think that. Maybe for her no but I do think that.
Int:   Yes
Par:   It is the same when I go to put on socks and I have to call her to put on the shoes.
Int:   And do you, at times, feel . . . how do you feel about her having to help you?
Par:   I feel uncomfortable.
Int:   Yes, why?
Par:   Because I am not used to it. At times I would get up and even help make the bed.
Int:   And that makes you feel bad?
Par:   One naturally feels bad but you have to be satisfied with God.

In discussing the assistance case 11, categorized by FIM score as a moderately independent stroke survivor, rated a 4 on grooming and dressing upper body tasks, and a 3 on dressing lower body tasks, receives from his family, the participant’s wife tells the interviewer that his granddaughter is “very good about helping her grandpa.” The illustration used as evidence of this is the description of how the granddaughter takes care of case 11’s foot which causes case 11 a great deal of pain due to poor circulation. In describing the type of intimate attention the granddaughter gives case 11, the participant’s wife tells the interviewer that the child does not “help him dress or anything
like that,” indicating that such assistance may be too personal for a young girl to provide for her grandfather.

As the following extract indicates, interpersonal body work must not only take into account the stroke survivor’s level of functional ability and his desire for assistance, but it must also account for the body as a material symbol of desire. We often relate to others through our bodies. Using cultural resources in shaping knowledge structures, case 11’s wife essentially conveys that some bodily relations are appropriate for grandfather-granddaughter relations and others are not. Thus, some caregiving practices will be okay for the granddaughter to perform, and others should be reserved for one’s spouse. The fact that the granddaughter does not help Grandpa get dressed is not because she is poor at caring for her grandfather, but because such dressing work is understood to be somehow inappropriate for her, a female adolescent, to assist in.

Int: Do they help you around the house?

Par: Yeah.

Wife: ‘Cause she's very good about helping her grandpa. Very good about it. The way she does his foot. She wipes his foot, cleans his foot. Um, well, she don't help him dress or anything like that but, if he goes outside she makes sure that he gets up and down the stairs, puts him, she's real good with him, I mean, she sticks with him. Really, I mean she does.

Like others included in this section, case 10, categorized by the FIM as a moderately independent stroke survivor, rated a 4 in grooming and bathing tasks, and a 2 on dressing upper and lower body and toileting activities, discusses dressing and bathroom work as the activities that are the hardest for him to perform independently. With the participants categorized as moderately independent reflecting upon such bathroom and dressing work as problematic in everyday life, such illustrations provide
qualitative support to their lower FIM scores in comparison to others who do not reflect upon such activities as being much problem. Those highly independent stroke survivors who do discuss bathroom and dressing work mostly remark that they have experienced marked improvement over the past month, or indicate a high degree of familial care provided to them that they gladly accept as positive social interaction. In other words, those who are rated as moderately independent generally do require at least a moderate or minimal degree of interpersonal assistance in bathroom and dressing work, while those who ceiling out on the FIM, rated as highly independent, offer a variety of lived experiences when reflecting upon such everyday routine activities.

Int: When you need help, what do you find most helpful?
Par: Dressing.

Int: Dressing is the hardest?
Par: And my bath. Yep.

Int: And getting a bath and stuff. That's the hardest part?
Par: Yeah.

When asked if there are times his body does not cooperate, case 10 answers “yeah. My right leg.” He relates this lack of cooperation by his right leg with getting dressed. His leg does not move on its own, so case 10 must pick up the leg and place it into his trousers. In the next extract, the stroke survivor objectifies his leg, referring to the leg as “it,” describing to the interviewer how he picks it up and holds it up. When asked how he feels about this uncooperative limb, case 10 states that “it’s the breaks of life.” Again, this loss of physical functioning is seen as part of life one must adapt and adjust one’s self to. For many of these stroke survivors, their body, which in the past has been
unproblematic in accomplishing the mundane activities of everyday life, has now dysappeared, and due to a loss of physiological self-control, they find themselves negotiating with their corporeality, while also attempting to keep their sense of an independent self intact.

Int: Are there times when you tell your body to do something and it doesn't cooperate?
Par: Yeah. My right leg.
Int: Your right leg. Uh-uh.
Par: When I'm puttin' on my clothes and I'm trying to get my pants on, you know, I have to take my hand and pick up my right leg because it won't-
Int: Yeah.
Par: I can't pick it up myself you know.
Int: Yourself. When you pick it up. Yeah.
Par: I pick it up and hold it up.
Int: How does that make you feel when you have to do that?
Par: Well, it's the breaks of life.

Case 13, categorized as moderately independent on the FIM one month after discharge from the hospital, rated a 4 on grooming, bathing, and dressing his upper and lower body, describes the problems he faces. In the extracts provided in this section, for many stroke survivors the negotiation between a sense of independence and one’s physiological ability seems to come to the fore everyday when accomplishing such “early morning tasks” as taking a bath, shaving, and getting dressed. In fact, case 13 states in the following extract that getting dressed is the only problem he has.

Int: What are you most worried about, if anything?
Par: Nothin' but like I say try to put on my pants and stuff like that. It take a while to put my pants on. And if I get ready to button my shirt it take a while to button it with my left hand, with the finger. And they feel, they kind of hurt, they’re numb, when you fasten the button it's kind of hard. That's the only problem I got.

Case 13’s following extract offers another illustration of a stroke survivor who prefers to perform functional tasks on his own, null of interpersonal assistance. The advice case 13 offers other veterans who return home after having a stroke deals with “a lot of things he can’t do.” The examples of such things that one can’t do are putting on one’s own pants and shaving. Even though case 13 “can’t do” these things he continues to try his best to accomplish such tasks, because he does not “want to call nobody.”

Interestingly, case 13 describes a conversation he has with his reflexes. When holding a razor, his reflexes fail to tell him to close his hand fast enough. This sort of dialogue between one’s self and one’s reflexes illustrates how stroke survivors negotiate corporeality in everyday life.

Par: When he get home? Well, I'll tell him there's a lot of things that he can't do and expect that he can't hardly put on his pants and uh, like I try to shave and it kind of hard for me to shave. It's certain ways you gonna probably have to get help, somebody help him shave. There's a certain way you had to hold a razor and stuff like that. There's a lot of things you can't do.

Int: Um-hmm.

Par: I said, well, I know there's a lot of things I can't do but I try my best to do 'em. I don't want to call nobody.

Int: What are some examples of some things that you try to do on your own?

Par: What? Shave.

Int: Um-hmm.

Par: ‘Cause you got to hold the razor a certain way. When you do that. When you catch a ball you got to hold your hand a certain way to catch a ball or you can't catch a ball. ‘Cause my reflex don't tell me to close my hand fast enough to grab it.
While many of the stroke survivors included in the sample state that the mornings are the best part of their day, some also describe it as the toughest part of the day. In describing his morning routine, case 22, rated as completely independent in performing all FIM motor activities, describes why mornings are tough for him, stating that upon returning home after his stroke, taking a shower became quite a chore for him to accomplish. Case 22 describes how he felt during the days he spent in the hospital post-stroke, telling the interviewer that he was “vegetative.” He did not want to get out of bed. Case 22 did not feel comfortable having a woman he did not know help him shower, illustrating the interpersonal relations that go on when performing body work. The stroke survivor wanted to be left alone, but his brother would not allow case 22 to “get away with that crap.” The participant sees this interpersonal negotiation between he and his brother as an example of why he is “very lucky.”

Meeting another veteran who had had a stroke during his hospital stay, case 22 saw the other stroke survivor’s interactions with his mother, telling the interviewer that the man’s mother let her son get away with too much. Although case 22 is divorced and living alone, his brother frequently spends time with the stroke survivor, not allowing the participant to get away with such “crap.” Thus case 22 is fortunate because now, although mornings are still difficult, he feels like getting out of bed and trying to accomplish self-care tasks like showering and dressing. Interestingly, case 22’s highly independent functioning may be largely because he lives alone and has a brother who encourages him to get up out of bed and do the self-care tasks that need to be done.

Par: But ‘cause what happened when I first came home, lets get back to that, in other words I didn't want to do anything. Everything was a chore. Get up in the morning take a shower. It was a chore to sit on that bench and do a shower like that. I did it
in the hospital and most of the time I would do it alone cause there'd be more men
and be women right? Not that it's not embarrassing. It’s just I prefer, if you're a
guy I prefer to just leave me alone right?

Int: Right.

Par: I mean they're sweet and nice and everything and they're there standing out the
door ‘cause God forbid something happens right?

Int: Right.

Par: But it's a chore. And so everything became a chore for me. That was when I
didn't want to, eventually I didn't want to get out of bed.

Int: Yeah.

Par: Just leave me alone you know? You're vegetative. That's how you feel. But I
realize how lucky I am because I became friendly with one of the guys, veterans
in the hospital and he's there four months now and he still can't stand up without
toppling over. It's a shame but he doesn't do the right thing. His mom tried to
help him but she lets him get away with…You see my brother doesn't let me get
away with crap.

Although “fortunate,” case 22 still sees mornings as the worst part of his day.

Taking a shower and shaving takes much more time than it did prior to the stroke.

Functioning time is one of the central issues stroke survivors must re-negotiate.

Showering and shaving, once taken-for-granted morning tasks, are now hard work
requiring a great deal of energy and personal effort to accomplish. Case 22 describes
changing his razor blade and shaving at night instead of the morning because of the extra
time now required to perform the activity. As the following extract describes, the
participant doesn’t like the mornings because it now takes him much longer to “get
going,” than it did before the stroke.

Int: Okay what's the worst part of your day

Par: (Sighs) let me think, I think really the worst part of the day is getting started in the
morning when I realize I got to shower, I got to shave. Shaving takes me a long
time. I just changed that blade when was it? Friday. I shaved whenever it was, at night, because it just takes me too damn long.

Int: Yeah.

Par: I don't like the morning when I have to get going.

Int: So the mornings are tough?

Par: Tough, yeah.

Similar to case 22, case 25, divorced and now living with his mother after spending some time in an assisted living facility, finds the worst part of the day to be morning time. Although still capable of dressing himself, case 25 relies on his mother to turn the shower on for him and provide general supervision during bathing. This is reflected in his FIM rating at one month in which he is rated a 6 on grooming, bathing, dressing, and toileting activities. The participant also describes the difficulties he has when shaving, indicating that he recently cut his face, and that he frequently leaves “patches” that his mother goes over for him. Thus, while categorized as highly independent by the FIM, the stroke survivor experiences the supervision and minimal assistance in self-care tasks provided for him by his mother as the major change after his stroke. As the next few extracts illustrate, these changes are reflected upon the stroke survivor as problematic experiences in his everyday life.

Int: Okay, who do you get dressed in the morning does your mom help you?

Par: No I dress myself. Only she turns the shower on.

Int: Okay.

Par: But other than that I do everything myself except for cleaning. I can't walk or I can't use my right hand.

Int: Right. But you do all your bathing, shaving, grooming, and everything?
Par: Shaving? Well, I cut myself a lot while I shave.

Int: Wow.

Par: You see the cut on my face?

Int: Just one.

Par: That thing bled forever.

Int: Oh.

Par: And I leave patches always and she's got to go over them.

The help case 25 requires during bathing and grooming are examples he provides in conveying how the stroke “kicked me in my ass.” As he informs the interviewer, “I was a young man.” The interviewer agrees that case 25 is young, suggesting that his age may make his corporeal negotiations even more frustrating. Apparently, once people get “old” they can expect functional loss. As the following extract indicates, for someone who is still a “young man,” such physiological changes are more “frustrating” because they are not expected.

Int: She touches up?

Par: Touches up right. This kicked me in my ass. The stroke.
I was a young man.

Int: Yeah you are really young.

Par: Yeah.

Int: It's probably even more frustrating.

Par: Yeah.

When case 25 says mornings are the worst part of the day because he has to get dressed, the participant then says that even the evenings are tough because that is usually when he takes a shower. This extract illustrates that it is not necessarily the time of day
that impacts corporeal experience as much as the tasks that are to be performed. Case 25 says that he needs his mother around when he showers because, due to his inability to walk, if something happens in the shower the participant’s life would be in serious jeopardy. This leads the interviewer to ask if having someone around during the day makes the day go better. Case 25 answers that he needs somebody around right now and it is something he has to get used to. This illustrates the type of transition stroke survivors commonly face during their return home from corporeal independence to the need for physical assistance.

Int: What's the worse part of your day?

Par: Umm (long pause) probably when she comes in and says hello in the morning (chuckles). No I don't know what the worse part of my day, in the morning.

Int: The mornings are tough?

Par: Yeah, mornings.

Int: Getting up? Getting ready?

Par: ‘Cause I gotta get dressed.

Int: Yeah.

Par: Yeah. And well even at night though when I jump in the shower. You know and I have taken showers and it's not daylight you know. I'm taking it before 6:00 before she goes cause god-

Int: something might happen?

Par: If she, if something happens to me in the shower…

Int: That's true. So does it make a difference having her around or having somebody around during the day? Does it make it better?

Par: Yeah I need somebody around right now. I do, but I got to get used to it.
While most of the participants in the sample live with a spouse or other family member, a few of the participants, such as cases 22 and 28, live alone. As seen in the current section, some of the stroke survivors require at least moderate interpersonal assistance in dressing, going to the bathroom, and bathing. Of these participants some enjoy the interaction they have with family members that they otherwise may not have, while others prefer not to receive physical assistance, preferring to perform such activities independently if it is at all possible. When no one else is around, however, the only choice the stroke survivor (as described in case 22’s extract provided above) has is to do the best he can on his own. As case 28, a participant categorized as highly independent, not requiring any assistance with any self-care task, states, once he takes his shower and brushes his teeth he feels comfortable and “good to go.” As the following extract indicates, this bathroom work, however, has changed. For instance, he is not able to shave with his right hand like he used to do. Realizing this, case 28 does use his left hand to shave, but also continues to “practice” with his right in an attempt to regain the tactical performance he once had. The interviewer finds these efforts “good,” informing the participant that he must keep practicing.

Par: But, most time once I get up and take that shower and brush my teeth I feel comfortable and I'm good to go.

Int: How did you figure out what you can do and what you can't do?

Par: Oh, because for instance like the bathtub, the bathroom?

Int: Uh-huh.

Par: I thought I could, and then, like shavin' I thought I wouldn't be able to shave no more after that. I know I don't, I could shave a little bit with my left hand but I want to be able start to shave with my right hand like I used to do. And I did on that and I kept doin' it, practicin' all the time. So now I can shave pretty good with it, you know.
Int: That's good Mr. Harris. You just gotta practice that.

This type of practicing is similar to the activities described in the extract from case 22 who discusses not wanting to get out of bed initially, but is now attempting to perform his everyday activities on his own, although they take more time than they did in the past. Case 22 seems to give credit to his brother who didn’t put up with his “crap.” Cases 22 and 28 are representative of stroke survivors who are trying to “get back to normal.” Those who are around the stroke survivor frequently view these attempts in a positive moral light, such as the interviewer who encourages case 28 to keep practicing. Stroke survivors who accept the physiological changes resulting from the stroke event are commonly seen by those around them as someone who has given up hope, as well as a person who no longer has the determination to live independently.

For case 25, a 40-year-old man, the stroke is expressed as having “kicked him in the ass.” This sudden assault on one’s corporeal independence is dealt with differently among the stroke survivors, but there appears to be two general categories of handling the situation. Some choose to do as much as they possibly can on their own, while others decide to allow those around them to begin performing certain aspects of self-care that used to be routinely done independently. Those who try to perform these routine tasks on their own may be seen as working hard to get back to their previous level of functioning, or as case 17 discusses, they may be seen as resisting necessary interpersonal assistance due to feelings of embarrassment. Those who do accept interpersonal assistance may be seen as giving up, or as putting their self aside and accepting the care loved ones and medical professionals are there to provide for the individual. Recovery from stroke, therefore, seems to be a delicate balance between working to regain lost functionality and
coming to grips with the reality that they must rely on others in order to perform certain tasks.

As stated, when there is no one else around to offer assistance, the stroke survivor has little alternative but to rely on his own body for functional performance. In the next extract case 28 offers an interesting description of how assistive devices may or may not be implemented to help negotiate corporeality after stroke. This in-depth discussion of assistive devices is particularly interesting when considering that case 28 lives alone and his only assistance is provided by such devices.

Par: Yeah, they told me, said I wouldn't be able to get in the tub unless I had those things up they gave me. So, and when I first come home I said well who gonna put 'em up?

Int: Right.

Par: I can't do it. I can't even walk. I'm on the walker.

Int: Uh-huh.

Par: You know. What do they think out there? That I want, I'm gonna put them things up?

Int: Right.

Par: Marry (visiting nurse) ain't said she was gonna put 'em up 'cause she probably don't know how to do 'em I guess. I don't know. But she never mentioned nothin' about that. I guess she had faith that I could bathe without that. And so I can get in the tub and get out, you know.

Int: Um-hmm. Were the things in there or was that-

Par: Without 'em.

Int: Without 'em? Oh go on Mr. Harris. That's good!

Par: Yeah.

Int: That's real good.
Par: But I be very careful, though.

Int: Right.

Par: 'Cause you know the tub so slippery.

Int: You don't want to slip, uh-huh. You got a little mat in the tub? One of them little things that-

Par: No. Matter of fact we was suppose to got one today I didn't even, I forgot to tell her (snaps fingers).

Int: Okay.

Par: We'll put one in. We get one tomorrow.

In discussing the shower bars the VA gave to him, case 28 wonders how the health care provider expects him to mount the bars. The visiting nurse never mentioned putting the bars up, so case 28 concludes that the nurse “had faith I could bathe without that.” And so, while concerned he may fall, case 28 continues to get in and out of the bathtub without assistance. The interviewer asks if case 28 has a mat to help prevent him from slipping in the tub. The participant answers no, but he was to get one that very day. Unfortunately he forgot to inform the nurse, and so will get one tomorrow. So, while being provided with an assistive device, the shower bars, and wishing to have a different kind of assistance, a rubber mat, case 28 has gone the first month of his recovery without the aid of either. Thus, for some, functional independence may be more arbitrarily than it is willfully determined.

The final extract provided in this section comes from case 27’s narrative. In it, the participant, rated as completely independent in all FIM motor tasks except stairs (rated a 6), discusses his continued ability to shower and dress on his own, as well as being able to drive. Even so, as the participant states, the process of stroke recovery is “hard for
me.” In saying that his ego is smarter than his brain, case 27 tells the interviewer that he “can’t handle not being able to do what I always do.” Widowed and currently living with his girlfriend, loss of functionality has impacted case 27’s sense of an independent self. Currently 51-years old, all case 27 knows how to do is work, and since the stroke he has not been able to do what he knows to do. As a person who is used to having “things under control,” not being able to work has been difficult for the participant, both emotionally as well as materially. As case 27 says in the following extract, he’s always had his bills paid. He’s always been used to having money in his pocket. Now, all his girlfriend Jan and he have are a “couple of quarters.” Thus, even those who are still able to functionally perform bathroom and dressing work on their own may still be faced with negotiating corporeality due to not being able to functionally perform other tasks, such as paid labor.

Int: So now what's a typical day like for you, you get up in the morning nobody helps you get ready?
Par: No I get…
Int: You get up on your own?
Par: Take my shower. I get dressed. Get the kids up. Well I usually just holler off the top to get up (chuckles) and they just they get up and get in and take their baths and get dressed. And as soon as she comes home from work around 7:30, 8:00, I take ‘em to school and then since then I've just been coming back here since I'm supposed to rest. It's hard for me. I've got too much, I don't know, ego. It's smarter than my brain I guess because I just can't handle not being able to do what I always do.

Int: Right.
Par: All I know how to do is work, and I can't work and it's, it's, you know.
Int: Right.
Par: Emotionally it's really hard. I'm just used to always having things under control. Always had money in my pocket. Always, my bills were all paid.

Jan: Now we have change in our pockets. (chuckles).

Par: You got quarters honey. We got that.

Jan: I sit there and shake my purse and say oh I hear a couple of quarters.

This section on bathroom and dressing work has illustrated how one’s body may dys-appear when attempting to perform mundane tasks most people take for granted, such as going to the bathroom, putting on socks and shoes, putting on pants and a shirt, shaving, or taking a shower. Once the body appears in everyday life as something that can no longer function the way it used to, individuals are faced with renegotiating who and what they are as human beings. Some may feel embarrassed about needing help in getting into a bathtub or putting on one’s pants. Others may not be overly concerned about needing such assistance, particularly if their spouse is around to help them, or if it is a way for them to have close interpersonal relationships with children and grandchildren. Other stroke survivors may become frustrated, upset, and angry over such corporeal shifts, desiring to be employed or to perform outside tasks such as yard work and home repair and maintenance. Stroke survivors must also balance a willingness to accept the help that is offered to them with the desire to perform tasks independently. Such a balance must be socially constructed within the face-to-face interactions grounded in routine, daily experience.

Transference and Mobility Tasks

In numerous examples provided in the section on dressing and bathroom work, part of the work in which stroke survivors need physical assistance is directly related to transference and mobility issues. For instance, case 1 describes the importance of
keeping his “limbs movin’.” Case 17 talks about his hesitation when getting out of bed for fear of his leg buckling. Case 18 discusses the assistance he receives from his 11 year-old son when walking to the bathroom. Case 30 conveys the importance of thinking, writing, and walking to his everyday life. Case 11’s wife details how the participant’s granddaughter assists him when walking up and down stairs. Cases 25 and 28 mention their inability to walk, using a wheelchair and walker respectively when accomplishing mobility tasks.

In other words, much like eating and medication maintenance, when discussing everyday life, stroke survivors’ narratives are often stories that weave together tasks commonly separated from one another in clinical measures like the FIM, thus illustrating the synergetic experience of embodiment in lived reality. The following extracts present illustrations of routine transference and mobility tasks that stroke survivors now, or at least during the acute stroke period did, find to be problematic in everyday life. For instance, in the first extract provided in this section case 26, rated as moderately low functioning according to his one month FIM score (motor = 30; total = 63), describes how when he first checked into the hospital he couldn’t move. However, now after being home for a month, everything is back to normal. Initially, case 26, an 83-year old male, didn’t even have the strength to roll over in bed. Two to three days later, he managed to regain his normal physical strength. Rated a 3 in grooming and transferring from a bed, chair, or wheelchair, rated a 2 on dressing tasks, and rated a 1 (complete assistance) on bathing, toileting, and toilet and bathtub/shower transfers, case 26’s recovery is by far the most dramatic in the sample. As the extract indicates, once one regains their functional ability, one sees their self as well as their world as returning to normal. The participant’s
medical records indicate he performs bowel movements in diapers and has been wheelchair bound for over two years after onset of epilepsy. Things being normal again for case 26 are certainly different than how normal is experienced by other stroke survivors. When case 26 discusses things coming back to normal, he mainly focuses on transferring from bed to wheelchair, which he can do with moderate assistance rather than maximal assistance.

Par: Yeah I didn't have any strengths. My strength was I couldn't turn over in the bed and I'd sit there hours just staring with nothing and she and I were still laying in bed and I could, I'd just mumble to her and after I got to the VA everything came back to me after two or three days.

Case 1 also discusses the acute stroke period, discussing how he was unable to get out of bed. His legs felt as though they had gone to “sleep.” His right side “kicked back in” after about five minutes, but his left side did not. Whereas case 26 states that his bodily strength has returned to normal, case 1, although rated as completely independent in all transfer tasks, informs the interviewer that the muscles in the back of his leg are still “real tight,” noting that the leg is not as moveable and flexible as it used to be.

Int: Okay. So, who, was there anyone different around in the afternoons before you had this stroke?

Par: Well, out here, yes, they always by, but nobody but me, I was alone, they had went to town. I had set up and went to sleep and when I woke up I couldn't get up. Well, I, through life, I've had my legs go to sleep, you ever had it? Do you ever had your leg go to sleep?

Int: Yes, sir, ha ha ha.

Par: Well, your right side kicked in, about 5 minutes, it kicked back in, but my left side and my knees looked like, and my biggest problem is my muscles in the back of my leg, they seem like they real tight. Well, it just ain't moveable and flexible like they used to be.
Case 14, whose one month FIM rating indicates he only requires supervision or set-up when transferring from bathtub/shower, provides an interesting illustration of how stroke survivors determine if they are back to normal. In discussing his first stroke experience, case 14 details how upon realizing that he had a major stroke he decided that he “had to get well.” Going from a “well person” to a “sick person,” was “very devastating.” A widowed 82-year-old living in an assisted living facility, case 14 decided that it was either “me or nothing,” so he began to work “very, very hard.” The participant states that it took a little over a year for him to get back to what he “would call normal.” Although he still had “problems,” he was able to play golf. He got out there and “fought it back.” In the extract that follows, this “fighting attitude” is linked by case 14 with his previous career in professional sports. Being in professional sports in the past is seen as helping him “a great deal mentally and physically,” after his stroke event. As the extracts provided so far illustrate, getting back to normal, is defined, as well as physically oriented to, differently by different stroke survivors, even if they are categorized as similar bodies according to their FIM rating.

Par: But I want to say one thing. That it's very devastating. A stroke is very devastating. The first stroke, when I fell on the floor and I couldn't, went to get out of bed and I was totally paralyzed on my left side. I couldn't speak or I couldn't eat. I couldn't speak. I couldn't swallow when they got me to the hospital I didn't understand until then that, I was totally conscious of everything, but when I got to the hospital they explained what's happened to me and then I realized that I had to go by myself. I had to. It was either me or nothing so I had to. I had to get well and I was gonna get well and I worked very, very hard. It took me over a year to go back to what I would call normal, and I still had problems but I was, I went back and I said I was gonna play golf and I did. Not good (chuckles), but I did get out there and I fought it back and being in professional sports when I was younger helped me a great deal mentally and physically.

As presented in the last section, case 17, rated on the FIM as completely independent in all transfers, informs the interviewer that “nothing has changed except
that I realize that I cannot get up too quick unless first sometimes [I] sit on the side of the bed before I move.” In this way, case 17 prepares his self for the task of transferring out of bed to the bathroom. This preparation seems to be the only thing case 17 finds to be not the same as before. In a similar fashion, case 15, also rated as completely independent in all transfer activities, discusses getting up in the morning. He describes how he rolls himself out of bed due to continuing arm and leg discomfort. Bed transference is referred to as a “job.” This married 46-year-old stroke survivor describes his daily life as struggling to get out of bed, eating breakfast, going back to bed, struggling to get out of bed again, going to the park, then returning home. The stroke has made case 15 tired, so he “stays in the bed relaxin’.” This extract provides further detail in how such daily struggles reflected upon by stroke survivors are often overlooked by such functional measures as the FIM.

Par: When I first get up, I'm, I'm speaking from, from today, okay? Or would you like for me to take on a weekly basis.

Int: Just when you get up in the morning

Par: When I get in the morning, I roll myself out of the bed, and, that's because my arm and my leg still hurts, and it's like tryin' to come up, out, to fill myself for the day because my arm and leg still hurts and it's a job.

Int: Does your arm and leg just hurt in the morning?

Par: It's hur, it hurts all, all the time.

Int: Okay.

Par: It feel, it feel like your froze in it and I got something puffed up in my chest and maybe, here's somethin' else.

Int: So, what usually happens in the morning after you get up?

Par: Uh, after I get up, eh, I go eat, eat some breakfast and then I go back to lay down.
Int: Is there anyone home with you in the morning when you get up?

Par: My wife is usually home, and the kids, you know.

Int: What about as the day go on, goes on, what about lunch?

Par: Lunch? I'm still in my bed.

Int: You stay in the bed?

Par: I stay in the bed relaxin' because the stroke made me tired. I don't know why but it makes me tired.

Int: And what about the rest of the day, in the afternoon?

Par: I get up and I go to the park and set down and I come back home.

While case 15 continues to struggle getting out of bed, case 10, rated a 4 (minimal contact assistance; stroke survivor performs 75% or more of the task) in all transfer activities, accomplishes bed transfers through the use of an assistive device he refers to as “the trapeze.” While this device enables him to get in and out of bed, as well as helping him turn over in bed, case 10 is still concerned about falling out of the bed. Since he does not have a bed with guardrails, his sister stays in the room with him to ensure he is safe. Thus, as the following extract illustrates, having a family member able and willing to provide such supervisory duties is often very important in determining whether a person is able to live at home or requires the support offered by an assisted living facility.

Case 10’s motor FIM score of 51 indicates that he indeed does require assistance in certain self-care tasks. With such needed assistance, it is his sister and various assistive devices that largely enable case 10 to enjoy home life following his stroke.

Int: So do you think um, in terms of assistance like, that you got-

Par: Well they gave me the trapeze on the bed and heck, do you all want to go in and see my bed? It's got a trapeze and everything on it.
Int:  Yeah. When, when we take, yeah.

Par:  They gave, yeah, the trapeze

Int:  To help pull you up.

Par:  Pull me up. Turn me over. See I have problems turning over at night because I can't get up to turn over.

Par:  Now I tried to get a, I asked for a hospital bed, but Dr. Zahn wouldn't give it to me. Said they couldn't.

Sister:  Sometimes I think he might roll off the bed at night or somethin'.

Int:  So it doesn't have guardrails?

Par:  Don't have any guardrails. Now see, I've got a twin bed is what I sleep on.

Int:  Okay, so that kinda um...

Par:  If I had a hospital bed I'd feel more safe at night see because-

Int:  Right.

Par:  I might fall off of that one.

Int:  Hm-mm.

Par:  No guardrails.

Sister:  So I sleep in the room with him.

Par:  She sleeps in the same room with me. She kind of listens for me at night.

Int:  Yeah. So um, it would have been helpful if you had the-

Par:  Hospital bed, yeah.

Case 31, whose FIM rating indicates he requires an adaptive or assistive device in transferring from a bed, chair, and tub/shower, states that sometimes while getting out of bed, he forgets about his leg. His knee won’t bend. It gets “stuck” creating situations where the participant is afraid he may fall. He has not fallen out of bed yet, able to stay
upright by supporting his body through reaching his hand out, placing it against the bedroom wall. Case 31 informs, “if I could lift my foot so I could walk there would be no problem.” Interestingly in the following extract it is the interviewer who uses a metaphysical entity as the determining factor stating, “if God permits.”

Int: In relation to your body, you already told me your leg and your arm, are the two things that worry you most.

Par: With regards to everything else, I feel pretty well. Sometimes I forget, when I am getting up from my bed, I forget (laughs) about my leg.

Int: Have you fallen?

Par: I've been about to, but I didn't.

Int: Be very careful.

Par: I held on to the walls. This knee doesn't want to bend, it's stuck. (Laughs; demonstrates for the interviewer).

Int: Ahh, it is stuck right there.

Par: But if I could lift my foot, so I could walk, there would be no problem. It might get better, I don't know.

Int: If God permits.

Case 31 then discusses a few falling incidents he had during the acute stroke period. He tells the interviewer that the worst time was when “it,” the stroke, first happened. He could not move at all, falling at the hospital as he was attempting to sit in a chair. Upon returning home, the participant fell by the door of his house. Case 31 states that he was a little weak, but now he can walk. The interviewer uses this part of the participant’s narrative as evidence of physical improvement stating, “So, in a month you have already improved some. Because you can walk, right?” Case 31, although moments before saying that if he could lift his foot so that he could walk there would be
no problem in getting out of bed, now tells the interviewer that he can “walk well enough.” Similar to a few other extracts provided previously, this seemingly dramatic shift in his walking ability seems to be linked with the use of an assistive device; his walker. In getting out of bed, divorced and currently living with his son, case 31 relies on the bedroom wall for assistance in maintaining balance, while at other times he uses his walker for assistance. Case 31 then adds that he finds the walker he’s using “uncomfortable,” and would prefer to use a quad cane.

Par: It was worst when it first happened, I could not move.

Int: You could not move?

Par: I fell at the hospital. I was trying to sit on a chair. I fell, and had to wait for them to come pick me up from the floor.

Int: That was like a month ago, right?

Par: And here, when I first came home, I fell by the door.

Int: Trying to walk?

Par: Yes, I was a little weak, but now I can walk.

Int: So, in a month you have already improved some. Because you can walk, right?

Par: I can walk well enough. I want to see if they would change this for me, for a simple one with four legs.

Int: Ohh, okay.

Par: This one is a little uncomfortable.

Int: Hmm. The walker. Is it too big?

Par: This was the very first one they gave me. With the one I fell over there. So, I took it back, and they gave me this one. But now, I feel a little stronger, I need the other one because I believe I walk faster.

Int: Hmm. More convenient. Is the other one smaller?
While cases 10 and 31 discuss the use of assistive devices in helping with transference and mobility tasks, cases 19, 2, and 3 discuss the importance in having other people around to help them with such functional activities. The first extract provided below is case 19, a 57-year-old stroke survivor whose FIM score indicates that he requires an adaptive or assistive device in all transfer tasks. Although supervision may not be absolutely necessary in a clinical sense, in the social sense those who care for the participant do find such supervision an important part of everyday life. Case 19 discusses how “somebody is always there” to watch over him when he is doing something, particularly when he is attempting stair mobility.

Int: Do you think they're more, they pay more attention to you?
Par: Oh, they, yeah I think they look more closely now when I'm doin’ something. Especially if I'm outside goin' up and down stairs, somebody is always there.

Case 2, indicating the need for minimal contact assistance (stroke survivor can perform 75% or more of the task) when transferring from bed, chair, and tub/shower, and requiring an adaptive or assistive device in performing toilet transfer, is asked specifically about help his wife provides for him. In the following extract the stroke survivor provides an account of how she helps him get out of bed by pulling his arm. Case 2 states that his wife is “attentive to everything.” The interviewer then asks the participant to be more specific in terms of what activity his wife helps him accomplish that “touches him,” or affects him more. The participant responds by providing an account of walking to the bathroom when he decides to perform bathing or toileting tasks. As an example, case 2 details how he tries and tries to pour his own bath water, but he is unable to accomplish this action. His wife will then help him in completing the
task. When asking the participant to be even more specific in describing what his wife
does that impacts him, case 2 tells the interviewer that he can not explain to her what it is.
What impacts case 2 the most is that his wife “soothes” him by being attentive. The
example he provides is her offering her hand while case 2 prepares his bath. As the
numerous extracts provided thus far indicate, the interconnection of assistance and
feelings of love are often reflected upon by stroke survivors.

Int: Does your wife help you with daily things?
Par: She helps me, she helps me get up from the bed she pulls me by the arm.

Int: Yes and do you feel that you need her taking care of you and helping you with a
lot of things?
Par: Naturally… The best care she gives me is that she is attentive to everything.

Int: But is there something she does for you that touches you? That affects you more?
Par: Well, when I have to take a bath, at times to get up I have to call her.
When I am sitting trying to pour some water and I try and try but I can't and I
have to . . . she comes and gives me her hand and helps me get up. If I have to go
to the bathroom, she takes me.

Int: And, is there a specific thing that your wife does that impacts you?
Par: I can't explain to you what it is.

Int: This?
Par: Well the thing I like the most is that my wife soothes me, stays attentive, it is
something primary because normally she's good, after that…

The final extract provided in this section refers to case 3’s description of his wife as
his “backbone.” Without his backbone, case 3 says he’d be in a nursing home. “Let’s
face it. She does everything.” In providing an example of what his wife does, case 3,
whose FIM score indicates complete independence in transfer tasks, describes the night
before when he and his wife went to see their grandchild’s music recital. As an
illustration of “how bad it was,” case 3 details how he kept sliding to the left of the seat. Noticing this, his wife pulls her chair beside his, allowing case 3 to lean on her rather than fall to the floor. Whereas, people see walkers, wheelchairs, and quad canes as assistive devices that enable people to transfer in and out of chairs and remain mobile, they often do not necessarily see close personal contact between a person and their spouse as a case of a person who needs such help. As this extract illustrates, these “little things that people don’t see,” are often big things for stroke survivors to maintain a moderately high level of functioning.

Int: You said your wife is the backbone, what does that mean to you.

Par: (chuckling) Hell, if I didn't have her I'd be in a nursin' home. Let's face it. She does everything. Last night the youngest grandson had a concert. We went to that, to see how bad it was, I was settin' there goin' to the left like that, kept slidin' to the left, cause the left side's gone. It was in these here foldin' chairs. She pulls hers right up side of me, leans up there before so I can lean against her, instead of fallin' out of the chair.

Int: Um-hmm.

Par: It's little things like that, you know, people don't see.

This chapter has presented a variety of narrative extracts that illustrate the ways in which stroke survivors manage corporeality after their return home. From dealing with new shaving techniques to leaning on their wife as a means to maintain balance while sitting on a folded chair in a school auditorium, there are a variety of self-care tasks these participants perform that require continuous negotiation of accounting for their embodied self. While the specific task and the specific meanings provided to task performance may shift, the themes of corporeal management and self-negotiation are paramount in their descriptions of everyday life after stroke. This discussion of managing one’s bodily presence in everyday life leads into the theme of the next chapter, which specifically
outlines the meanings attached to locomotion, and how these stroke survivors account for the changes they are experiencing in locomotive functioning.
CHAPTER 7
SHIFTS IN LOCOMOTIVE ACTIVITY

Prior to discussing how shifts in everyday meanings are linked with shifts in locomotive activity, I will attempt to delineate the terminology of lived experience, embodiment, the embodied self, and corporeality. Hopefully this attempt will illustrate how meanings of the lived body, the self, and everyday experience are intertwined when taken into account by people who have returned home after a stroke event. In contemporary sociology it is not uncommon to stress the importance of bringing the body back in, or taking the body into account. In essence, this dissertation has been framed as an outline of schemes of experience for a group of stroke survivors.

The analysis of FIM and FAI measures presented in Chapter 4 is used to represent clinically produced schemes of the stroke recovery experience. Chapters 5 and 6 represent schemes of experience produced by the stroke survivors in the qualitative interviews conducted one month after returning home from the hospital. In chapters 7 and 8, the importance of changes in locomotive activity to one’s sense of self will be presented, as well as a description of the everyday activities beyond those of self-care that are reflected upon by the stroke survivors. Once locomotive and routine activities are addressed, the different schemes, or interpretive frameworks, that have been presented in chapters 4 through 8 will be compared and contrasted with one another. The next six paragraphs, therefore, are meant to serve as a theoretical bridge between what
has been presented up to this point in the discussion of medical knowledge and functional assessment in the everyday lives of stroke survivors and what is yet to come.

Mary F. Rogers (1983 p.38) defined lived experiences as interpreted realities, which implies that every meaningful experience involves a description. She added (p. 39) “reflective attention establishes discrete experiences. The reflective glance makes the prereflective unity of identity a unity of meaning.” The lived experience of stroke recovery can be described as giving one’s self over to medical experts, pharmaceuticals, God, or others in the home milieu. At the same time these stroke survivors reflect on their experiences as representations of how they continue to work hard at maintaining independent functioning in their normal routines, thus maintaining continuity in their interpretations of who and what they are. Some of the stroke survivors included in this sample express that most things have gone back to normal except for perhaps one or two aspects of daily life.

For many of the stroke survivors, however, things such as diet, medication intake, shaving techniques, and transfer ability have changed. Still, they remain hopeful that, with time and adherence to medical knowledge, these things will return to normal. This issue of having lived experience get back to normal is one of the most important issues stroke survivors deal with upon their return home. However, such an attempt to get back to normal does not necessarily imply a biographical disruption as much as it does a shift in how one negotiates among self, body, and world. That is, these stroke survivors may be the same person they’ve always been, and often they make a point to note that they are, but some of the ways in which they negotiate their personhood within lived experience has shifted due to shifts in functional ability.
One common aspect to the lived world is that it is interpreted as stable. Lived experiences are familiar. They are routine. This continuity of meaning in lived experience allows us to take the world for granted as a stable entity that exists outside our selves. Common sense understandings of the world inform us that reality continues. It is there to be observed. This natural attitude that the world is there for us and that our self is an object present and real in everyday life can become problematic when something such as having a stroke occurs. This is because the certainty of who one is and the taken-for-granted self is challenged by the body’s dys-appearance, that is the body appearing in the world as something that must now be continuously accounted for due to pain, illness, or loss of functional ability. When one’s understanding of their body as a taken-for-granted aspect of the world changes, lived experience, or the active interpretations of what is going on, also changes.

Yet there seems to be a strong commitment on the part of the participants to maintain a coherent sense of self, relegating the changes in their corporeality as something that requires interpersonal negotiation more than it does a new story of the self. At the same time, as will be seen in the current chapter, for those whose activities have greatly altered due to loss of independent locomotive ability, there exists a struggle between who one was and who one currently is. This struggle, however, often depends upon the reflections presented by the stroke survivor regarding the interpretations and accounts of social others. Shifts in self-meaning, therefore, are not simply a result of the illness, but also, and perhaps even more so, a result in how one’s body is interpreted by those around him.
As stated previously, the term embodiment denotes how the body is used as a way of constructing the self. In order to know the person, one must read the body. Embodiment is a term that expresses the material significance of the lived body when communicating identity. Holstein and Gubrium (2000) discuss how sociology has historically overlooked the body and in particular, aspects of the lived body and how it helps shape social relations. The important sociological concept of human agency has often been linked to mind, taking the body as a taken-for-granted entity. Noted at the start of this chapter, the lived body in late 1990’s and early 21st century sociology is often no longer absent in social scientific reports, but rather has become the focal point of study.

With growing sociological interest in the work of Michel Foucault and contemporary social theorist Bryan S. Turner (e.g. 1984; 1991), recent sociological theory is beginning to, as Maxine Sheets-Johnstone (1992) suggested, give the body its due. Holstein and Gubrium (2000 p. 230) stated that “the self survives because we continue to refer to it, speak to it, and act toward the entity that we take to be at our moral core.” As I have suggested, the story of the self often becomes a more embodied narrative when one’s body dys-appears. Not all people who have recently had a stroke event interpret their body as something that has dys-appeared, but some, particularly those whose everyday routines have become problematic after stroke, do express such a reorientation toward the body. Thus, understanding physical functioning takes into account everyday lived experiences, and both are made meaningful when one recounts, or reflects upon, the story of their self.
Testing One’s Limits

One of the major chapters in the story of the self for these stroke survivors addresses physical concerns related to locomotive activities. In chapter 6 the discussion of transference and mobility tasks deals more specifically with accounts regarding getting out of bed and moving around the house, such as walking from the bed to the bathroom. A few of the stroke survivors require interpersonal assistance in moving from one area to another, while others require assistive devices in order to perform such activities. In the current chapter, locomotive activities are expanded to the importance walking as a general activity is expressed to have in the everyday life of the stroke survivor. The FIM defines locomotion as: “includes walking, once in a standing position, or using a wheelchair, once in a seated position, on a level surface.” If one can walk at least 150 feet within a “reasonable time” without an assistive device then he is rated to be completely independent in the locomotion task. As this chapter will show, however, locomotion has far greater meaning to stroke survivors in their everyday lives than the way in which it is described on the FIM.

There are few stroke survivors who mention that walking is not that important to them, such as case 24, a stroke survivor with a perfect overall FIM score of 126, who states he was not a “marathon walker” before the stroke anyway. Describing his hand as a “flipper,” it is manual dexterity that this participant states to be the most limiting aspect of his body. While he may walk a little unsteady this is not experienced as a “big deal.” Not having hand dexterity like he used to is expressed by him as a greater concern.

Int: What are your greatest concerns about your body? Your arm?

Par: Well the hand actually. I don't care about the walking. It wasn't like I was a marathon walker or anything. The walking is a little unsteady. Big deal. It just takes me a little bit longer. But it’s not a major thing. It’s probably not even
noticeable, but I don't have the strength in my hand. I do have the strength but I
don't have the dexterity that I did have.

For the vast majority of stroke survivors included in this sample, however,
locomotive activity is described and outlined in extensive detail, with expressions of how
important locomotive activities are to their everyday lived experience. For example, case
3, rated a 6 (walks a minimum of 150 feet using brace or prosthesis, adaptive shoes, cane,
crutches, or walker. Takes more than reasonable time or there are safety considerations)
in locomotion, provides a detailed account regarding the importance walking has for him.
Much like shifts in medication maintenance has impacted case 9’s sense of who and what
he is, for case 3 changes in locomotive functioning have had a major influence in how he
constructs the story of his self. Complex narratives such as the ones provided by cases 9
and 3 help to illustrate how certain aspects to self-care and bodily practice intertwine with
virtually all components of everyday life.

Int: Is walking important to you?

Par: Oh, I gotta walk. Hell, I've, up ‘til, in October before this happened 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'll 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.

Int: Um-hmm. Did you like doin' that?

Par: Oh, yeah, yeah. You gotta. Walk six, seven miles with kids you better like it.
(both laugh)

Int: How often did you do it?

Par: Every day.

Int: Every day?

Par: Five, six, seven days a week.
Int: Now you can't do it anymore?
Par: I've walked right out the door out on the front porch and I'm give out.
Int: How do you feel about that change?
Par: Oh, it's bad. It's bad.

Prior to his stroke event case 3 would walk 6 or 7 miles a day around his local community with a group of children living in the area. This activity is intimately linked with case 3’s sense of self as he states, “we’ll go out there and walk, us kids,” indicating a sense of identity that is constructed from having actively participated in such walking endeavors. Prior to the stroke event, if one drove into the community and asked “where’s grandpa at,” all of the other kids would know exactly who is being referred to (case 3), and where he currently was. After the stroke event, however, life has changed. Case 3 no longer takes these daily walks with the neighborhood children. In fact, he fatigues just walking out to his front porch. When asked how he feels about this difference in locomotive activity case 3 responds, “oh, it’s bad. It’s bad.” Before the stroke, case 3 “was goin’ out all the time. All day ‘til dark.” Now being back home for one month, case 3 continues his attempt to go outside and perform activities, informing the interviewer, “they may have to roll me up in a ball and get me out there but I’ll get out there. I’ll go out.”

Case 3 discusses the changes in his neighborhood. Some people have left, others divorced. The older people have come and gone through time, with some of them “leaving” the participant. The “kids,” however, were always there. Walking with the neighborhood kids was one act the participant expresses as helping him in constructing a stable sense of his social self. Another activity that helped to construct the meaning of
who and what he was is his membership in the Keystone Cops. He practiced with the Keystone Cops and participated in parades. With these two activities, walking around the neighborhood with the “kids” and participating in the Keystone Cops, case 3 was “constantly doin’ somethin’.” As he informs the interviewer, “I didn’t sit down. You wouldn’t find me home probably.”

Int: Who was around then, the same people that are around now?

Par: No, some of ’em left me. Some of ’em moved out. They got divorced and stuff like that. You know, the older people. So the kids is all. But I was in the Keystone Cops for a time out here and we'd go out in different parades and practice, and go out on parades. And then the kids, we'd walk and I was constantly doin' somethin'. And I didn't sit down. You wouldn't find me at home probably. If you did you'd have to go out somewhere and get me. I was doin' somethin' all the time.

Before the stroke, case 3 says the best part of the day was when he could be at home resting. Now, after the stroke, case 3 is struggling to have the functional ability to go outside and do some of the things he used to do. His sense of self prior to the stroke was organized around outside activity. One month after having the stroke event, due to fatigue, loss of balance and other locomotive difficulty, case 3 is struggling to maintain a coherent sense of self.

Int: What was the best part of your day before your stroke?

Par: Probably when I got to come in and set down and rest a while. (laughs) That's probably what it was.

Int: So, overall, has your stroke made much difference in what your day is like?

Par: Oh, Lord, yes. You wouldn't find me in the house settin' around.

This physical change in daily life has had an impact on how case 3 views himself as a person. As case 3 states, he’s still a person, but such changes “make you a little odder.” Now dependent on his family to physically help support him in public, case 3
finds himself looking for a bench to sit down on, anticipating the arrival of his personal motorized transporter. Until his motorized cart arrives, it is up to his wife to assist in case 3’s locomotive activities:

Int: Can you give some details, some examples of how she does it?

Par: Oh, sure, grabbin' my hand, helpin' me. Help straight up and down, keepin' me from fallin'. She'll walk along side of me every now and then and, when I need her. You can tell you know why I'm a little more off balance.

Int: Um-hmm.

Par: She'll walk along; hold me.

Int: When you said, one example you gave earlier was that yesterday at the concert you were sliding and she sat by you?

Par: Yeah, she's sittin' on the left and she slid her chair right up against mine. Put her shoulder there where I can lean against her. Keep me a slidin' out, falllin' out of this chair.

Int: Are there any other times?

Par: Oh, yeah. Lot of times like that. She does different things like that. She sees it ahead of time and a lot of times we start in the store she'll sneak up beside of me, just accidentally, you know be aside of you. She ain't trying to tell you nothin' but I could see it (laughs).

Int: And she does that for what reason?

Par: To keep me from fallin' and bustin' my backend (laughs).

In discussing what’s most frustrating in how others relate to him, case 3 again mentions how family members will walk alongside him to assist him in bodily balance while he is mobile. This assistance may be a major difference in case 3’s life, but he says that his family members do not “feel sorry” for him. For example, when receiving assistance from his grandchildren, case 3 tells the interviewer that his grandchildren simply interpret such activity as “helping out with grandpa.”
Int: What do you find most frustrating about how others relate to you now?

Par: I, really, they just walk along with me and help me, that's the biggest thing. I need help and they give it to me. I don't know whether that's frustrated or not, but it's...

Not only do family members such as his wife and grandchildren assist him in locomotive activities, but when out in public case 3’s wife works at masking such assistance by sliding her chair close to her husband’s, or sneaking up beside him “accidentally.” These seemingly inconsequential actions by his wife have important consequences in how well case 3 functions in the public milieu. Case 3 has noticed a change in public locomotive activities since the stroke event and anticipates another change once he receives a motorized assistive device. These physical changes that are experienced in case 3’s public functional activities are also linked with changes in his sexual performance as he reflects upon going down the store aisles seeing “what the women look like.” As he says, “that’s all I can do anyway; see what they look like.”

Par: I'm still a person as far as that is. I just can't do the things like I done before. I have to have help on other things. My two grandsons, two daughters and a wife, they help me all the time. It just makes you a little odder. When I started out she has to walk along aside of me or close to me. We go to a restaurant I find a seat and sit down. Don't walk around. Or, go to Wal Mart, I get me a bench and sit at. That's one thing that's gonna change when I get that three-wheel cart. At least I can go down the aisle and see what the women look like. That's all I can do anyway; see what they look like. But, I mean...

Moving away from how family members see case 3 after the stroke event to how those he does not know view him while he is out in public settings, case 3 reflects on how people react to seeing someone with a walker, and how these reactions make the stroke survivor feel good as well as bad. He feels good that people “respect the disabled,” but feels bad because he is “disabled.” This awareness of his physical limitations is a “hard thing” when “you’re not used to it.” The interviewer asks the participant what is the
“hard thing?” Case three answers that the hard thing for him is “grabbin’ that walker.”

Now instead of getting his own coffee and carrying it back into the living room, case 3 relies on his wife to do these things. This illustrates the difference in who and what case 3 is before and after the stroke event. That is, rather than a person his family can rely on to provide physical assistance, he is now a person who must rely on his family for such help. What makes this shift in embodiment more problematic is that it is readily visible to all around him, including those who do not intimately know case 3.

Int: When you go out, like to Wal Mart, or to shop and do other things in public, do you have any thoughts or feelings about how others are reacting to you?

Par: Oh, yeah. You'll start down an aisle, somebody will see you usin' your walker, and they'll step back out of your way and stuff like that. It makes you feel good but yet it makes you feel bad. You know, that people respect the disabled but yet it makes you feel bad because you are disabled. It's a hard thing to do when you're not used to it.

Int: What's a hard thing?

Par: Grabbin' that walker. Grabbin' this cane, every time you go anywhere or do somethin', wheelchair or somethin' or other. That's the hard part. And I pushed a wheelchair many a time with my sister in it. She has muscular dystrophy. But she grew up with it. Time she was 5 years old on she don't know any different. Now she's bed ridden. So, it gives you an idea of how they feel now.

Int: Um-hmm. And how's that?

Par: Disabled. You know, you can't do things the other people do. Time I go get a cup of coffee it's cold by the time I get back because (laughs) it's courage, you know, takes longer. That's the reason why I got her. She does all that stuff....

In reflecting on whether case 3 is reluctant to go out in public because of how others view him, case 3 says he is not reluctant to do things because of what others may think. As he tells the interviewer, “you think bad of me, I'm sorry. I mean hell, I don't care.” What case 3 does care about is how he feels about his self when he loses balance while walking and bumps into people he does not know. This is why his wife is always
beside him during public locomotive activities. Now when they go to the store, case 3 will sit down and drink some coffee while his wife shops. When friends or acquaintances of case 3 happen to pass by, they will stop and chat with him while he remains seated, drinking his coffee. As case 3 states, he knows what is going on. He just tries to make the best of it.

Int: Are you ever reluctant to go out because of how you think others will view you?
Par: It's not that I'm worried about them viewin' me and stuff like that. It's that I'm afraid that I'll run into people, or knock 'em down while you're off balance or somethin' like that. That's the reason why she's always by me. Unless we get like I said at Wal Mart, we'll get, I'll get back to the cafeteria, she'll bring me a cup of coffee and I'll sit there and drink on that, sip on that, while she does her shoppin'. Then, she'll come back by and ready to go and we'll start again. But I'll run into two or three people that I know or they know me, you know, and we'll talk awhile.

Int: How others think of you or view you doesn't really make a difference to you?
Par: It don't bother me what other people think. I know what goin' on, you know? Just like you. You think bad of me, I'm sorry (laughs) I mean hell, I don't care.

At a later point in his narrative, case 3 continues to discuss the practical problems he now experiences when attempting to physically maneuver in public settings. He feels “bad” about the change, but family members, such as his grandchildren who “run interference for grandpa," help alleviate some of the negative aspects that have resulted from the physiological changes after the stroke event

Int: What problems would you tell the person he's likely to run into when he's out in public?
Par: Biggest thing is people. A lot of 'em don't pay no attention where you got a walker, a cane, or crutches or whatever, and you have to watch them. They ain't gonna watch you. They'll walk on top of you. Some of 'em. Not all of 'em. Some of 'em go out of the way to get people out of the way, but the biggest problem is that a lot of people walk on top of you. You have to watch 'em.
Int: Well, you said earlier, you said one thing about people getting out of your way and that was good and bad?

Par: It, well, like when I go into a store and stuff like that they'll see you comin' and they'll step aside out of the way. Or before, why they'll let you bump into 'em, you know, they don't pay no attention to you. Now, they kinda pay attention to you if you got your walker and stuff like that, yeah.

Int: And how is that bad?

Par: It's bad that they have to. It's not bad that they want, well they want to get out of your way. It's bad on me if they don't cause I'll fall (laughs).

Int: It's bad ‘cause they have to and, I mean, why is that?

Par: Because I bump into 'em, and I'll lose balance and I'm gone. Yeah, them grandkids, they'll run interference for Grandpa. Let somebody else walk into them first.

Another aspect that case 3 mentions as problematic is when people he does not know ask “all kind of questions” when they see him staggering. Such questions make case 3 acutely aware that he is different from others, and that this difference is materially visible to those around him. That is, without his family “accidentally” providing physical support, case 3’s “awkwardness” is readily noticeable not only to him and his family but by others that are around him in public settings. Not knowing that case 3 has had a stroke, some people conclude he is a “dummy,” which as case 3 explains is someone born with a mental impairment. Such conclusions “bother” the participant because his “awkwardness” then becomes not only who and what he currently is, but for those who did not know him before the stroke, who and what he has always been. Such conclusions, therefore, erase, or wipe out, case 3’s biography. In order to minimize such situations, family members run interference, offer covert physical support, or he sits down and enjoys coffee while his wife shops.
Par: Oh, 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... Well, you take somebody that's never been around and they'll ask you questions, you know and they'll ask things, and that bothers you.

Int: That bothers you?

Par: Well, that bothers them that, you know, that they would see me staggerin'.

Int: Oh.

Par: I can't lift with my left hand. It's just, it's odd, you know, that they think he's odd. Anybody that's 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 (laughs).

Int: Were there any other types of reactions you think people would have?

Par: Nah, I'm not seeing a whole lot except maybe I'm sorry for you or somethin' like that. That's about all. Look at you like you're a dummy.

Int: Um-hmm. They look at you like you're a dummy? What does that mean?

Par: A lot of people figure that it's cause you can't walk and keep up with the rest of 'em there's somethin' wrong upstairs. In other words, you're a dummy. They can't see nothin' wrong with you, it's gotta be all in your mind, which really it is but they don't look at it that way. Like you may have been born with this birth defect or somethin' or other. Somethin' of that order.

Even with these problematic aspects to performing activities that require prolonged locomotive functioning, case 3 says he goes ahead and does what he has to do, but gets a "bit shook up," when he finds something he wants to do and is unable to accomplish it. The participant provides an example of some woodwork he recently attempted to do out in the front yard. When failing to carry a 2 by 6, case 3 gets angry at his self. Learning to live with functional failures is seen as a necessary step in no longer being angry at his self when failing to accomplish an activity he would have been able to accomplish in the past.

Int: How do you feel about these changes?
Par: Really, you ain't gonna do nothin' different, so you just go ahead and do what you have to do.

Int: Are you frustrated about things now that you weren't frustrated by in the past?

Par: (laughs) Yeah, I can't do things like I want to do 'em. I get a little bit shook up, you know? I can't grab that 2x6 and walk out like I could before.

Int: Do you feel angry, or sad about-

Par: 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. I'll fall and bust my, yeah (laughs).

Int: Do you think anyone else feels-

Par: That's just somethin' I'm gonna have to learn to live with, you know (clears throat).

Case 3 continues his reflection on learning to live with functional failures, detailing how he skinned his knee while attempting to build a wheelchair ramp on his front porch. Case 3 describes how when skinning his knee, he became upset with his self. This time, however, the participant brings up the notion that age may have something to do with loss of physical functioning as he remarks “age gets you; it don’t get you,” linking shifts in his bodily presence to shifts in time.

Int: So you cut your leg? How did that happen?

Par: I skinned it and fell working on that ramp out there. I was doin' somethin' I normally do, but it didn't do. I didn't get up like I should. I mean there's different things like that, that you want to do and you start to do it and you don't do it. Age (grunting) gets you, it don't get you.

Int: How do you feel about, like when you fell, what were you thinking or feeling?

Par: You wouldn't want me to say that on tape, what I was thinking (both laugh). There's a little bit, I put twenty years in the military and there's a little bit of four-letter words that you wouldn't want me to say. That's how I felt, though. Dumb, odd, it hurts, and a few other words that I'm not gonna add.

Int: So, dumb, odd, it hurts?
Par: (laughs). Well I could say a few more words but they wouldn't be too pretty.

Int: What were you thinking, were you blaming yourself or were you upset at-

Par: Yeah, at me. Upset with me.

When asked what advice he’d give another veteran who has had a stroke, case 3 states that he has never thought about giving advice on the topic. Even so, he manages to make a keen distinction between two groups of stroke recovers; namely those who get up and go outside and those who express contentment with staying inside their home. Case 3’s advice is to follow the actions of the first group, which is described as going to one’s “limit.” When someone reaches their limit they may sit down and rest, returning to their activity once the fatigue level has dissipated. As the participant informs, “there’s a lot of stuff that you can do if you would.”

Par: I'd never thought about it. About givin' somebody else advice. Just do what you have to do, I'd say. I mean, a lot of people can get up and walk and go on and there are people that want to sit around

Int: Um-hmm.

Par: I'd say, go to the limit. In other words, if you can walk, walk. In other words, don't live, if you can't, in other words, go to your limit, set down and rest and go back. There's a lot of stuff that you can do if you would.

According to case 3, when testing one’s limit it is important not to feel sorry for your self. His observation is that “if you stop, your body is gonna stop.” In reference to one’s body, case 3’s advice is to “keep movin’ it.” While separating “you” from “your body,” case 3 is also noting that “you” can only go where “your body” goes. Therefore, taking “your body” to its limit is taking your self to its limit.

Int: Why would you give them that type of advice?
Par: Don't feel sorry for yourself. See, why I'm sayin' that cause if you stop, your body is gonna stop. Keep movin' it. If you don't it's just gonna be there right in that one spot.

The participant also presents another example of how changes in his locomotive activities relate to changes in his interpersonal relations. While conducting the interview, two neighborhood friends stop by case 3’s home. The participant uses his activity during their brief visit as an example of the changes he has been experiencing since the stroke event. Rather than case 3 initiating physical interpersonal contact, it is now up to others to do so.

Int: You said it's going to be a whole lot different. What are some examples of how it's going to be different?

Par: Well, I can't walk where I want to. I can't run with the kids and play with 'em. Get the wife to fuss at me no more (laughs).

[Advice to another veteran]

Int: What problems would you tell him he's likely to run into when he gets home?

Par: The walking, the, a lot of times it will affect your speech. It didn't mine. Mine's already been affected. But ah, these things, getting' around doin' things. I have a hard time doin' that. When I've done things all my life and all of a sudden I can't do nothing. You may have noticed there when they come in I didn't jump up, shake hands and all that. Normally I'd a met them at the door or out there outside, and I'd a hugged her, shook his hand and would've come on here. It don't do that anymore. You sit where you at and let them come around.

When the interviewer asks if anything beneficial has resulted from the stroke event, the participant has difficulty thinking of something “good” about what has happened. The only thing “good” case 3 can think of is the help he receives. Again, while needing help brings forth a body that must be negotiated with in order to get routine things accomplished, the help one receives is interpreted as a positive aspect of familial relations. Interestingly, the help those in public settings may offer, such as
moving out of case 3’s way as he walks down an aisle, is seen as respectful but also a reminder that he is different from others. The help he receives from his wife and grandchildren on the other hand, are indicators of love, affection, and understanding. His family knows what is really going on, while strangers often ask “all kind of dumb questions,” and may even conclude he is a “dummy.” For case 3, locomotive activities not only shape how he sees his self since having a stroke and how he interprets the way others are seeing him, but locomotive activities also help to shape the way he interprets other selves around him.

Int: Anything else about your recovery that you think you'd say is good? Something beneficial for you?

Par: It's kinda hard to figure anything, cause you're not used to it. I was in there walkin' real good and I could do as I please like that part, walkin' and getting' around and all of a sudden I can't. So it's hard to figure out what would be good and what would be bad, ‘cause there's already bad, you know. It's hard to figure out what would be good about it.

Int: Since you were released from the hospital up ‘til today?

Par: What's good about that? I don't know, just about the help I get, I guess.

In case 3’s narrative, the stroke survivor describes how he has tried to test his functional limits in building a ramp on his front porch. Case 29, also rated a 6 on locomotion on the FIM, offers another interesting example of how one may test physical limits. Case 29 states that the stroke event has not limited him too much. He still drives, walks and does things around the house. He just does these things a bit slower than before. He describes himself as the type of person who needs a challenge in order to try things. As an example of the kind of person case 29 is, he reflects on some comments made while in the hospital. He refused any type of assistive walking device. He was determined to walk on his own and that is what he is currently doing.
Int: Some people say that time is more of a burden after a stroke. Some people like to spend a lot of time convalescing. Others prefer using their time.

Par: Not for me. I drive. I walk. I do things around the house. It hasn't limited me that much. I am just taking it slower.

Int: So you are saying that before you were always doing things or you were busy?

Par: Uh-uh.

Int: And now you are taking things a little slower?

Par: Uh-uh. But I am still doing things. I am a person that if there is not a challenge for me I wouldn't even try it. And that's why I told them, when I was in the hospital, I'm not getting no wheelchair, no cane, no walker. I'm gonna to try it on my own. And I did.

When out in public, case 29 recounts shopping activity that is similar to case 3. Case 29’s wife does the shopping while he sits down and waits for her, for as the participant states, he does not have the “resistance of walking behind her all the time and running around the isles.” Although this activity closely resembles the activity of case 3, while case 3 is anticipating a motorized 3-wheel cart, case 29 is not considering the use of such a device. Not being able to move through the aisles of local stores is not problematic to case 29’s sense of self; at least not as problematic as would be the use of an assistive device for locomotive activity.

Par: No not many changes because I go to the store and most of the time if I go with my wife she does the shopping. I sit down and wait for her. And that's exactly what I am doing now because the only thing is I don't have that resistance of walking behind her all the time and running around through isles. I just go and have a seat. Relax and wait until she is finished.

Not using an assistive device for locomotive activity while in public settings indicates to case 29 that others are not interpreting him to be “different” or concluding that he is, as case 3 puts it, a “dummy.” Avoiding these kinds of interpersonal interpretations is more meaningful than is increased mobility in public through the use of
a walker or motorized wheelchair. As case 29 informs the interviewer in the following extract, often when he tells others he has had a stroke they do not believe it. The interviewer seems to agree, stating “I am looking at you now and wouldn’t be able to tell.” Case 29 tells the interviewer this is because “I do things normally.” These things that case 29 is referring to are specified as driving and walking.

Par: They don't even know unless I tell them, I mentioned to some people I had a stroke about a month and a half ago and they look at me and say what! I don't think so.

Int: I am looking at you now and you wouldn't be able to tell so...

Par: Because I do things normally. A lot of my neighbors didn't know I had a stroke because they see me driving and they see me walking around. I have a limp on my right leg but it doesn't slow me down. The only thing I can't do is run so far and I am going to.

In the next extract from case 29’s interview, the participant tells the interviewer that he does have a limp, but the only effect the participant has experienced from it is that he cannot run as fast as he did before. The limp, therefore, presents him with a challenge. He will keep exercising until he is able to run like he used to. The exercising the stroke survivor is referencing, however, is not necessarily professional physical therapy or running on a treadmill. Case 29 presents an example of his locomotive ability, reflecting on a recent experience where he was playing with his young grandchild, chasing him around the house. Thus, exercising is described as playful interaction with family members.

Int: And you're going to?

Par: Oh I am going to for sure 'cause I am gonna keep exercising until I get into that shape that I can run. I was chasing my grandbaby last week around the house. He said you can't catch me. You can't run. And I was running after him and that's the most difficult thing to do trying to run after a child that is three years old and everyone is so fast and they don't look where they are going and they run into things and I was chasing her.
When the interviewer mentions the limp, the participant is quick to describe the limp as “little.” This indicates that it is only slightly visible and can be more readily overcome than more severe physiological ailments. In the extract below, case 29 does state that he is concerned with balance, but “that’s about it. Nothing else.” Again this concern is similar to the one case 3 has, but the two of them reflect on this concern in quite different ways.

Int: So even though you do have the limp…

Par: A little limp

Int: Nothing that is really residual?

Par: That's it. The only thing that concerns me is the balance. Sometimes I lose my balance a little bit but that's about it. Nothing else.

Like case 3, who had a cane and wheelchair in the home, case 29 does use assistive equipment. His equipment, however, is not immediately visible when he is out in public. Case 29 uses “platforms” in his shoes to help stabilize his body while in motion. As the participant states, these are not noticeable unless he tells someone. In essence, case 29 walks “like a normal person.” As the stroke survivor indicates in the following extract, without these platforms, case 29 has difficulty walking “normally.”

Int: You said you noticed maybe a limp but you really don't think about those things?

Par: No because I run with these platforms in that I put inside the shoe that keep my balance and people don't even notice that I have a limp because I got this and it balances your feet, your bones and when you walk it’s not noticeable. Only ‘til I tell you, ‘cause I just walk like a normal person.

Int: A normal person. Without the shoes do you have some problems with your walking?

Par: Yeah, a little bit.
Int: A little bit.

Par: Yeah, because the balance. It isn't alright.

When asked what he does to make his body work better, case 29 again reflects on his assistive equipment. Having seen them on television while in the hospital, case 29 decided he would order one and try it, rather than a cane or walker. He even switches the device from shoe to shoe. Thus, this extract and the others that have been provided by cases 3 and 29 show that normality can be maintained as long as one’s abnormality such as using a device to maintain balance, is not immediately visible to social others.

Par: It makes your body work better, so I guess the platforms would be something like those. Its an orthopedic thing they sell on tv. I saw it. I was watching tv at the VA and I said I'm gonna get me one of those. I got the information somewhere around here maybe I and when they got here they say in the paper give 'em time to break in. They are really hard. And then you notice when they are loosening up they work for me. I use 'em in both feet. I move them from shoe to shoe.

Case 30, rated as completely independent in locomotion on the FIM, states that age is not of major consequence as long as he can “think, write and walk right,” further noting that like cases 3 and 29, he too will sit down and wait for his wife to finish shopping whenever the two of them go to a store. This change in public locomotive activity is one major theme reflected upon by the stroke survivors and illustrated in such extracts as the one provided below.

Par: Yes. Even when I go with her shopping or somethin'. We haven't been shopping too much 'cause we go walk around or shop, whatever. I get tired. I go sit in front of the store, wait on her. I don't care how old I get as long as I can think, write and walk right...I want to walk on my own and think on my own. And I don't care how good if I get to be 100, okay.

For case 28, rated a 6 on the FIM in locomotive activity, a stroke survivor’s interpretation of their physical condition is extremely important. As he tells the interviewer in the following extract, “say in your mind, I'm gonna make it. You know,
I'm gonna be out walkin' again. And I'm gonna be good at what I did before and I'm gonna do it again like I did before.” While this understanding and dialogue with one’s mind is important, according to case 28 so too is rigorous physical conditioning. This extract illustrates a seemingly dualistic perspective where one must maintain mental health as well as working on physical health, described as different sets of activities. However, both components, mind and body, are seen as necessary components to the self one lives by.

Par:  You know, just do whatever you have to do in rehab, PT and stuff like that. You'll be okay.

Like many of the stroke survivors in this study, case 28’s greatest concern is walking. Similar to cases 3 and 29, case 28 finds that when he participates in locomotive activities he is often “off balance.” Since returning home after the stroke event, the participant has discovered that altering the speed of his gait alters his ability to maintain physical balance. Case 28 wants to run, “but it won’t let me.” His biographical reflection provides a self-description of case 28 as a “fast runner.” Now if he attempts fast locomotion case 28 loses his balance. His body therefore, becomes not only an object that must be negotiated with, but an obstacle that impedes case 28 from actualizing his true self. As he tells the interviewer, “But in my mind I want to run… Well it'll make me feel good if I could run. I know I still can run, you know?” Now, to walk at a “kinda” fast pace case 28 must use a “stick,” or cane.

Par:  My greatest concern?

Int:  Uh-huh.

Par:  Walking.

Int:  Walking?
Par: Um-hmm

Int: What about it kind of concerns you?

Par: Uh, you know sometimes I can walk and be off balance. And then I know that 'cause if I walk slower I be on balance. Be alright. If I try to walk like I used to walk, fast, you know I get like a little…

Int: Yeah, a little wobbly.

Par: I said oh, hold it. Better stop. Go and walk slowly. I want to run and it won't let me. You know I can run a little like. Not far. But in my mind I want to run… Well it'll make me feel good if I could run. I know I still can run, you know? Not real, I can walk fast. I can go fast, you know. Kinda fast with the stick, but I can't run.

As case 28 reflects on the use of a cane to assist in his walking pace he also mentions the help provided to him by the walker he had. Case 28 then compares and contrasts the different assistive devices he has, telling the interviewer he would not recommend one of the devices to other people. He would tell them to use the walker, wheelchair or cane. This extract from case 28’s interview, along with several others provided in this dissertation, show the importance assistive devices have in enabling stroke survivors an opportunity to go out and perform public activities they performed prior to having a stroke.

Par: You know the walker I had? Now that really helps.

Int: Really?

Par: Um-hmm. Matter of fact I got another one over there they gave me.

Int: Oh, I see it.

Par: That'n okay but that wasn't too good. I won't recommend nobody that use that type, you know?

Int: Uh-huh.
Either the walker, wheelchair or this.

Or the cane?

Social Perception

Similar to case 3’s discussion of how others in public react to seeing the stroke survivor, case 28 says that some have mercy for him and some do not. That is, some people will shift their locomotive speed to the pace case 28 now moves, but others continue their same gait, forcing the stroke survivor to try to walk as fast as he did in the past. Case 28 concludes that the ones who do not alter their pace must see the stroke survivor as the “same old Iceman.” Some of his friends do not alter their understanding of who and what case 28 is, but his body makes such a reorientation towards his self a practical necessity. Known by others as the “Iceman,” this nickname brings forth certain imagery of an independent, strong, steely-cool, man. As indicated in the extract below, after the stroke however, case 28’s body is unable to maintain the material reality of the imagery his name denotes.

Some people. Some might have a little mercy for you and then some don't. Yeah, you know, some take up time with you and some'll lead you like you can still walk as fast as they can. And then the other one behind you tryin' to help you make sure you don't fall or look watchin' ya, you know. And then, and I'll get in my mind that the one that doin' that, dog, he ain't no different when I was, you know.

Than before, uh-huh.

Yeah. She must think I'm still the same old Iceman. That guy used to be (laughs) like she say come on, come on, come on we got to go (laughs). You know.

A similar change has occurred when case 28 goes shopping. He used to just go in and walk around, but now relies on a cane to maintain his balance. In the next extract the participant describes how people will at first rush the stroke survivor, but upon seeing the assistive device apologize and walk around him. This example helps to define what case
28 is referring to when he mentions people “aggravating” him. While people say “excuse me sir,” and walk around case 28 as a way of being polite and not irritating the stroke survivor, such activities make him very aware of the differences in who and what he was before the stroke and who and what he is in the present moment.

Par: It seems to be a little different. Because I could just walk in Publix, get a uh, push cart or whatever and then go ahead and do my regular shopping. And nobody's gonna aggravate me. But like now I go in there with a stick.

Int: Uh-huh.

Par: Seein' like peoples, (chuckles) I don't know look like be behind you. They rushin' ya and you look up, "Oh, excuse me, sir, excuse me, oh excuse me".

Int: Right, skirtin' around you.

Par: Yeah, scootin' around instead of seein' somebody walkin' like that. They just go around, you know. Make sure they don't irritate him. And that's the only thing that I get when I go to the store like that. Well some of 'em react like, walk right on by you like, I guess you nobody or I don't care. If you walkin' like that or not, you know. And then some of 'em go by uh, "how ya doin'?" Just like that. Give you a smile or somethin' like that. Then some of 'em will hold the door for you and then some of 'em forget, "Oh, I'm sorry" and they'll push the door like that and go on about your business.

In comparison to the locomotive difficulties and interpersonal negotiations that occur in public space, many of these stroke survivors find walking in or around the home less “aggravating.” For example, in the following extract case 31, rated a 6 in locomotion on the FIM, states that he walks in his backyard, describing a recent time when he and some family members played a game together until late in the evening. Thus, while able to walk, the stroke survivor limits his walking activities much more than he did prior to having the stroke. Now, locomotion is performed with and near family members in familiar, intimate settings.

Par: I walk around the backyard. I go back there, and I sit with them over there. The other day we were out there until eleven o'clock playing a little game.
Int: Playing dominoes?

Par: No.

Daughter: No, playing Hot Potato

(Everyone laughs)

Case 31 states his desire to “improve from this leg.” He wants to get better so that he can function in public settings the way he did prior to the stroke event. Once very independent, fishing for a living, case 31 now feels dependent on others in order to function in public. In particular, in the next extract case 31 relates changes in his level of independence in public settings to shifts in his locomotive abilities due to his leg.

Par: I would like to improve, improve from this leg. If I walk, it is difficult. I want to get better so I can go out like I used to before. I used to go everywhere. Fishing. I used to make ends meet.

Int: You felt more independent?

Par: Yes, more independent

Int: So, you miss that a little bit?

Par: I did not bother anyone. I do not like to depend on anybody. But this has me paralyzed practically.

Int: Your leg? So, if the leg would be alright…

Par: I would be walking all over the place

Int: So, you would be non-stoppable

Daughter: The leg.

Case 31’s obstacle is his leg. A part of his body has become an “aggravation.” His leg is expressed as the primary problem in everyday life. “The leg,” has changed who and what case 31 is. If his leg was the way it was before, the participant “would be
walking all over the place.” The participant continues to reflect on this experience, saying that he no longer feels like a “free person,” but rather now sees himself as “handicapped.” As case 31 informs in the extract below, there is a difference in these self-descriptors. One who is handicapped is not able to do his “own things.” For case 31, the change in functioning that is associated with his leg has altered who he was (a free person), to what he now is (handicapped; unable to do his own things). The only thing that impedes case 31 being a “free person” is that he cannot walk. But when he is able to function in public settings the participant feels “good.” His speech has not changed, and people are still able to understand him. It is only his locomotive activities that have changed.

Int: Has the stroke changed the way in which you view life?

Par: Yes.

Int: In what sense?

Par: I don't think that I am a free person versus a handicapped. There is a difference. You see yourself unable to do your own things. The only thing that impedes me from going out is that I can't walk. But when I go out I feel good.

Int: You feel good, secure when you are in public?

Par: Yes. I speak clearly. People understand me. I don't have any problems. I just hope time will make my leg get better. And here, when I first came, I fell by the door.

Int: Trying to walk?

Par: Yes, I was a little weak, but now I can walk.

Similar to case 28, who gives an account of which assistive devices he does and does not recommend, case 31 discusses how he would prefer a quad cane over a walker, finding the walker to be “a little uncomfortable.” Stating that he was given the walker
after falling by his front door, he now feels a bit stronger and thinks that he will be able to walk faster with a quad cane as opposed to walking with the aid of his walker. The following extract shows how the change in assistive device serves as a material representation for a sense of progress in physical, locomotive functioning.

Par: I can walk well enough. I want to see if they would change this for me, for a simple one with four legs.

Int: Oh, okay.

Par: This one is a little uncomfortable.

Int: The walker. Is it too big?

Par: This was the very first one they gave me. With the one I fell over there. So, I took it back, and they gave me this one. But now, I feel a little stronger. I need the other one because I believe I walk faster.

Int: Hmm. More convenient. Is the other one smaller?

Par: Yes. Is the stick with four little legs and with the shape of a cane.

The importance in such functional progress in locomotive activities is poignantly expressed by case 31, as he details his practical walking experiences in everyday life. As described in the next extract, in the mornings, case 31 feels a bit “heavy,” but as the day goes on “it gets better,” thus case 31 walks better. He spends all day walking “here and there,” with his main hope for the future being that he is able to walk better than he currently does. Locomotive improvement is linked to how things were before the stroke, when case 31 lived with and cared for his youngest son.

Int: Is there something that you do which makes your body feel better?

Par: To walk.

Int: To walk helps you?
Par: In the morning I wake up a little "heavy" to walk, but as the day goes on it gets better. I can walk better.

Int: Do you walk a lot or a little?

Par: I spend all day walking, here and there.

Int: All day walking. You will get thinner, ha ha.

Par: Aha!

Int: [A year from now] where do you see yourself? What do you expect to happen?

Par: I hope my situation has changed, and I'm able to walk better.

Int: Uh-huh

Par: So, I can go on with life like it was before. Working and taking care of my son.

Cases 3, 29, 28 and 31 are not exceptions but rather general representations of the current sample in terms of how these stroke survivors reflect upon the importance walking has on one’s sense of self, as well as how locomotive functioning impacts the shifts and changes experienced in everyday life. Interestingly, the extracts provided also detail how this sample of stroke survivors is “fortunate.” That is, a function that most of these stroke survivors have not found to be problematic in their everyday lives is their speech. Speech and locomotion are often coupled in the narratives. This functional coupling tends to follow this generic example: “luckily my speech has not been affected. I can still talk alright. But now, my walking… well that’s comin’ along slow. I need a cane or else I’ll lose my balance and I’m liable to fall.” Most of the stroke survivors included in this sample can still communicate who and what they are, but the physical presentation of self in everyday life has shifted from one of independence to one of dependence; be it dependence on other people or dependence on a locomotive assistive device.
The stroke may be reflected on as a major event that has changed one’s sense of embodiment. For instance, case 28 discusses how some of his friends see him as the “same old Iceman,” but for the participant he is not the same old Icemen right now because he cannot run as fast as he did before the stroke event. His goal is to run again, and therefore return to the “Iceman” he was prior to the stroke. In contrast, case 13, categorized as moderately independent in overall FIM score, but rated as completely independent in locomotive activity, tells the interviewer that the stroke has not impacted how he sees himself as a person because he is “Bo Gator.” People tell him that he doesn’t even limp. They ask Bo Gator to run a bit and he obliges them. A former karate teacher, Bo Gator does a bit of shadow boxing for his mother and a few intimate others, demonstrating “that I can move around pretty fast.”

Case 13 does not feel doomed because others remark that he does not look as though he ever had a stroke. In other words, case 13’s sense of self remains unproblematic in large part because those around him remark that his physical ability has “changed back” to resembling his “old self.” This physical improvement as expressed by others post-stroke, informs case 13 that he is still Bo Gator. In the following extract, the stroke survivor’s physical functioning immediately after the stroke is framed as an aberration to how it normally is. Now when people tell Bo Gator he hasn’t changed, this tells the stroke survivor that he is “back to normal.” Where normality as it relates to physical functioning is expressed as a certain score on the FIM, normality as the stroke survivors themselves reflect upon it is often rooted in the many social-interactional contexts that make-up everyday life.

Int: Do you see yourself differently as a person now that you've had a stroke?
Par: No, 'cause I'm Bo Gator. I call myself Bo Gator and I always say that I'm Bull Gator. Always believe in yourself. So anybody tell me say, "boy, you don't even limp. Let me see you run a little bit". I say, "Yeah, I, I'll do it". Say, "You used to teach karate". I show my mom and them that I can do certain things. Boxin', you know, and try to show 'em that I can move around pretty fast.

Int: Um-hmm.

Par: No I don't see myself doomed 'cause people see me, say, "Boy, you look like you never had no stroke 'cause people sayin' so much stuff about you".

Int: Um-hmm.

Par: "Boy, you look different.”

Int: Um-hmm. So with that in mind do you think that others see you differently as a person?

Par: They see me as the same person because they say, "You act the same.” They say you know you still crazy ‘cause nobody can keep a good man down. Bo Gator. No, like I say people look at me and they say, "Well, you haven't changed. See, last time you walked out of this hospital your arm was up like this. You couldn't move it. You was limpin' with your left side. Just look at you. You don't really limp. You can move your arm." See? Yeah, I say I can move it. I look at myself, when I was in the mirror, I say, "Boy, you still got it. You still the man.”

People tell Bo Gator that when he first left the hospital after his stroke, he was limping and had difficulty moving his arm. Now he can move his arm, as he demonstrates for the interviewer, and performs different activities that help represent his improved gait. In fact, he now tries to walk fast, but social others tell him to slow down. That is, other people around him are attempting to set functional limits, but as Bo Gator informs, “nobody can keep a good man down.” Bo Gator reflects looking at himself in the mirror and telling his self, “Boy, you still got it. You still the man.” Similar to case 28, case 13 reflects on who and what he is in terms of how others, and he himself, refer to him; namely “Bo Gator.” Bo Gator says that he realizes he misses a step every now and again and that his knee may not be the same as it used to be, but although people keep
telling him to slow down, Bo Gator feels he “had to show ‘em I could walk.” While friends of case 28 may expect too much in terms of locomotive activity from the Iceman, according to case 13 in the following extract, his friends underestimate Bo Gator.

Int: So now are there things you've learned on your own that you feel makes your body work better?

Par: Well, I be tryin' to, I try to walk fast. They tell me don't walk fast. Slow down. I'll be tryin' to walk fast to show people that I can walk fast. I can move like this. I'll show 'em, you know. They say, "Don't drive". I can show 'em I can drive. So I got to believe in myself. You know. . . . When I got out I guess I started walkin'. I feel like that with me I could pick up my feet a little faster. I said well I'm gonna see can I walk a little faster. And they told me to slow down. She tell me, "Slow down.” I said, "I see that I missed a step sometimes.” And then I kind of, my knee kind of wore out, missed a step. "Slow down, you walkin' too fast". And I had to show 'em that I could walk.

Similar to Bo Gator, case 22, rated on the FIM as completely independent in locomotion tasks, describes the first month of home life after the stroke event as a time of physical improvement. He describes for the interviewer how his arm no longer “hangs” and how he no longer “dribbles” out of his mouth. These two aspects to physical appearance are noted as the differences the stroke survivor experiences since returning home. He no longer “topples over,” is ambulatory on stairs, and can take his dog for a walk.

Par: I'm not walking down the street you know with my arm hanging and dribbling out of the mouth so there is a difference. I'm not toppling over and I can walk up stairs, down stairs, and walk my dog.

However, like case 3, among others, case 22 still notices differences in social perception when he goes shopping. Some help the participant out with little things such as opening a door for him, while others simply push him aside. As case 22 informs, people are in too much of a hurry and fail to realize the tribulations faced by someone with limited mobility. Case 22 refers to people such as himself as “handicapped.” Some
people are in too much of a rush to notice the limitations of the stroke survivor, but as case 22 states in the next extract, “actually most of the people are very kind to you.” This indicates dynamic social relations that are difficult to present in a consistent, just so, manner. As Goffman (1959 p.243) indicates, “life may not be much of a gamble, but interaction is.” In other words, the stroke survivor questions whether he will be credited or discredited in each public encounter he has with an unfamiliar social other. This extract from case 22’s interview marks a stark contrast when compared with the more predictable familial interaction where the stroke survivor most often remains a creditable person. Knowing the person’s biographical history can be an important factor in how the stroke survivor experiences the social encounter.

Par: I've gone in the mall and I'll be shopping or people open the door for you and they help you with the little things. It's the little things that they help you with. And I've had people come up and push you aside when they want. They're in a hurry and I think with handicapped people they shouldn't do that. They should, they don't realize that maybe some day they'll be that way themselves.

Int: So it's frustrating when people that don't care and just kind of-

Par: Well people are too much in a hurry today. They're running. They run here and they run here and I think it's just the people are in a hurry and they don't realize what they do. But they, actually most of the people are very kind to you.

Slowing Down

One common theme noted up to this point is that these stroke survivors have experienced their body “slowing down,” since the stroke. Many, such as Iceman and Bo Gator, reflect on how fast they used to walk. Case 17, rated as completely independent in locomotive activity on the FIM, does this as well, defining his pre-stroke self as a “buzzsaw” in regards to locomotive activity. He has slowed down “considerably,” stating that he is “never sure of this left knee.” His left knee, once a taken-for-granted component of his body, is now problematic to case 17’s lived experience. Not only does case 17 walk
slower, he also makes certain to avoid direct sunlight, for the sunshine causes case 17 “stress.” These differences in pre-stroke to post-stroke locomotive activity presented in the extract below are aspects to everyday walking activities that are not accounted for by clinical measures such as the FIM.

Par: I walk rather slowly. I don't walk as fast as I usually walk. I'm usually walking like a buzz saw but I've slowed down considerably because I'm never sure of this left knee. That's why I'm walking considerably slow now.

Int: So you say that sometimes you walk to the store?

Par: Yes.

Int: How often do you do that?

Par: Not very often. I would say maybe three times in a week.

Int: How far is that, that you walk?

Par: Well, not that one over there to, um, to Publix. Publix is about, would you say two miles? Mmm? It's about a mile, I would say, about a mile-and-a-half. So there [back to the] house is about 2 and-a-half miles.

Int: So you walk there?

Par: Yes.

Int: Do you have any difficulty walking to the store?

Par: No. Once I get started I maintain my same gait as far as my feet is concerned. I walk, I take my time and walk slow. And not in the sunshine, but on the shady side of the street so I don't have any stress with the sunshine.

Case 17 also notes that he does not use any assistive device to aid in locomotive activities. He just walks by himself. The following extract indicates that his self is something separate from a cane or walker, but something that is connected to, or with, his body. Thus, the body as object is still an object that is more intimately connected with one’s personhood than is an object such as a cane or walker. The participants in this
study frequently differentiate their selves from their body or a body part such as their leg, while other times they reflect on their selves as an embodied entity. This narrative shift in body as object and embodied subject may reflect on the stroke experience as a relatively recent experience. That is, at one month after the stroke, many participants are still in the process of reunifying one’s body with their self.

Similar to the other extracts presented, case 17 also discusses the notion of testing one’s limits, stating that he will sometimes “stretch out” attempting to walk at a faster pace, but “something” tells him he better slow down. This “stretching out,” and being warned that he is trying too much is another aspect to everyday lived experience that is commonly discussed by the stroke survivors. Whether it is carrying wood, dancing, fishing, or simply increased foot-speed, there are times when the body communicates to the person that he has reached his limit. This bodily communication and the examples provided of such body-self dialogue by the participants when reflecting upon their functional capability, are illustrative of how one’s sense of embodiment and one’s sense of self, while perhaps still reflected upon at times as distinct entities, are commonly experienced as highly dependent upon each other in everyday life. As the following extract from case 17’s interview shows, after stroke one becomes more aware of his physical boundaries and therefore, one’s body becomes a more salient aspect to lived experience.

Int: Do you use any devices to help you? Do you use a cane or a walker?

Par: No. I'm just walking by myself.

Int: How do you feel when you're out walking?
I feel pretty good. But sometimes I will try to stretch out and see if I can walk a little faster, but something tells me you'd better slow down so I go back to my same gait and I don't try to overdo it.

So you kind of pace yourself?

I pace myself, uh-huh. The only thing that has changed is my, I don't move as fast. I slowed down considerably.

And you get tired very easy.

And I do. I get tired very-

You get tired easily?

Um-hmm, I get tired quickly. Except when I'm driving. But, I don't overdo it. I don't walk too much. I try to stay within the boundaries that I can work in. It bothers me because I know that I cannot, my speed has slowed down considerably. It's like an elderly person driving a car who cannot react. My reaction time has slowed down considerably.

Case 17 also describes how others sometimes see his walking as similar to the locomotive activity of someone who is intoxicated. Case 3 mentions that others sometimes conclude he is a “dummy.” Case 17 states that people may look at him as though he were a “drunk.” One major theme in this section, as represented in the following extract, appears to be a loss of physical balance and how this shift in bodily appearance impacts interpersonal relations and publicly located definitions of one’s embodied self.

Because it has, my wife spoke to me the other day. She said, "you walk like you're drunk." Occasionally I will do that. It seems that my equilibrium is off and I will veer even to the, to the right side mostly, even though my problem is on the left side, but I will do that to the right side.

Case 14, rated a 6 on locomotion on the FIM, informs the interviewer that there is a “great deal” of physical and mental change after a stroke event. He adds that a person who has survived a stroke becomes more understanding of himself, as well as more
understanding of what is going on around him. This increased understanding of one’s self and one’s environment that is expressed in the next extract may be related to an increased awareness of one’s bodily limits and capabilities. Case 14 incorporates an interpersonal aspect to the experience, stating that “people are more helpful than you realize.” This extract from case 14’s interview seems to reflect the assertion that the body is the mediator between self and world, and that receiving help from unfamiliar social others is not necessarily a self-discrediting act, but may be an act of interpersonal self-recognition and respect.

Par: Physically and mentally there's a great deal of changes you don't realize. Well you're more, I think from day to day, I think that you're more understanding of yourself and more understanding of what's going on around you. And I think that people are more helpful to you than you realize.

Case 14 also discusses how sometimes his body does not want to do what he wants to do. In the extract that follows the participant states that his mind tells him “no,” but his body tells him something else. He wants to go and do what he wants to do, such as climb stairs or drive a car, but when he gets to the stairwell or to the automobile case 14 decides it is better not to do such things that he had easily done before the stroke event. This reflection on his mind and body dialogue is an illustration of how one negotiates between how one presents one’s self and how one manages physical limitations in everyday life.

Par: Well for instance, well I don't know if you want to go somewhere and you want to do something and your mind tells you no and your body tells you something else. And you want to go and you want to go and you wanna do what you want. Well I think it's one thing as when you want to do something. Like if you want to climb the stairs. You can't climb the stairs like you used to do and sometimes you want to drive a car and you'll know in your mind that you think well I can do it. But when you get, you don't want to take somebody else's life in your hands and yours also. So you just don't do it. That's all.
These functional limitations are the “drastic changes” case 14 is referring to. He informs the interviewer that he is unable to walk like he used to, and may require a ramp wherever there are stairs to physically navigate (FIM score on stairs = 2 indicating that the stroke survivor requires maximal assistance in performing the task). The participant goes on to describe possible writing difficulty, and how one must make practical physical adjustments in order to communicate via hand script. Case 14 discusses possible problems with eyesight and how vision and hearing deficits may result from comorbidities such as diabetes. The participant concludes by stating that whatever one’s functional limitations are, he must never give up. The following extract from case 14’s interview, as discussed, presents a detailed description of how frequently one must not only interpret the stroke experience, but other health issues as well.

Par: Well you gonna be, there's gonna be some drastic changes. You can't walk like you used to. You might have the steps that you can't get up. Climb up stairs and they're gonna maybe have to put a ramp or some kind of a board so you can get up there up and down. So you gonna have a lot of changes. You're gonna have changes in eating. You might have if you had a stroke on your right side and with your left hand will be unable to eat 'cause you're gonna complete change. And your writing. If you write letters, you’re gonna have a time with your right hand writing letters so you might have to learn to write with your right hand by holding your left hand to your right. And you might have to go ahead and do it that way. There's a lot of changes. And there's a lot changes to be made. And your eyesight might be impaired. So now especially if you're a diabetic. A diabetics when they have a stroke it's gonna be very, very, very hard to understand that maybe your diabetes will sometime will affect your hearing and affect your eyesight. But whatever, don't give up.

As stated, some participants, like case 7, rated as completely independent in locomotive activities, describe their body as something that is “wearing out.” Case 7 tells the interviewer that he doesn’t think any more about his body than he used to. He is just trying to keep “it,” his body, going as long as he can. But where case 14 discusses
disease as a major reason for physiological change, case 7 relates his body “wearing out” to the more general factor of aging. For case 7, time is of the essence, and as he lives longer the greater the likelihood that his body will no longer “go.” As he informs the interviewer, case 7 does not “get too involved” in walking or exercise. He has decided to take things easy and slow “like an old man ought to.” Thus, as this extract shows, not only must many of these stroke survivors negotiate with a variety of health-related issues such as hypertension and diabetes, but they must also negotiate between physical limitations that are directly related to the stroke, and limitations that simply a natural component to the aging process.

Int: Do you think any more about your body now than you did in the past?

Par: No, it's 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 (laughs).

Int: Is there anything specific you do to keep it going or to try to keep it going?

Par: No, ah, just don't overdo it is the main thing. I just try to take it easy and do little things. Don't do big things.

Int: Like what little things?

Par: Well, I get kind of tired if I get too involved in too much walkin' or too much exercise or, so I just do everything with moderation and kind of take it easy and slow. Like an old man ought to do. Act my age (laughs).

In the following extract case 1 (rated as completely independent in locomotion on the FIM) offers an account of time as healer. That is, through the course of time case 1 has experienced improvement. Improvement is interpreted as shifts in locomotive activity; namely case 1 no longer has to use a “stick” when walking. No longer needing a cane for locomotive activities illustrates for the stroke survivor, that through time, he is getting better. According to case 1 it is not testing limits that leads to improvement, but
rather taking it easy and allowing time to heal all wounds. Thus, for some stroke
survivors, one must continually work at achieving bodily improvement, while others find
taking it easy and waiting on time to work its magic as the best practical activity after
having a stroke.

Par: [I don’t] carry no stick or nothin'. One side is better than the other one.
So I know that and I don't want to distress myself because it takes time to
get well, I know, and it ain't gonna be just like a snap. Snap in and snap out.
I've been tryin' to stay on the day restitution you know. Takin' it easy…

Even though case 1 says he’s been taking it easy, in the next extract presented he
informs the interviewer that he feels good when he gets up early and “stirs around.” The
participant adds that when he says that he feels good it is in relation to his “sickness.” He
was sicker before. Now he feels better, even though his left side still does not “motivate”
as well as the right side of his body.

Well, I feels good when I get up early and stir around. I feels good.
I say good, you know, good from the sickness and I'm just motivatin' this.
It's takin' a little time, that's all... but the way I was, yes I'm better. Yes I is.
I have to say so. I don't have to use a stick. Now this left side, is not
motivatin' like this side. Now I can tell you that. Now I take some medicine.

Case 1 notes that “good” means better now than immediately after the stroke event.

By taking it easy and “waiting on time,” the stroke survivor hopes to get back to the
way he was. While not completely better, the participant has seen improvement as
illustrated by the fact that he no longer needs an assistive device for mobility. The
soreness he felt all over his body has dissipated, thus indicating to case 1 that he is
healing through time. In terms of “stretching out” or testing his physical limitations, case
1 states he does not “push it,” referring to his body, to cooperate unless he has to. This
distinguishes him from those stroke survivors who describe “pushing” the body as an
important factor in regaining functioning one had prior to the stroke event. As the
following extract shows, similar to case 7, case 1 seems to indicate that he has little
interest in testing his physical limits.

Par: Well I don't push it to cooperate then unless I have to, ‘cause I'm trying to get better
to build this body back to where I've been generally livin’ and feelin'. That's why
I'm around but I ain't far. I'm right here.

Int: So how has this changed since the last time I talked to you a month ago?

Par: Yes, yes I'm considerable feelin' better. I don't have to have a stick to walk.
But it's not completely. I don't know whether they ever get back to like it was, but
I'm better. Before I was so sore, honey, every time you, anywhere you touched, it
was sore.

Another stroke survivor who has decided not to test his limits is case 9, (rated on
the FIM as a 6 in locomotion and a 1 in stair mobility). As case 9 informs in the
following extract, testing his physical limits would kill him. While case 7 says that he
does not pay greater attention to his body, case 9 says that one must do so. According to
case 9 there simply is not a choice. If one does not pay attention to what his body is
“saying” to him he will be at major risk of fatality. As case 9 informs, he still has the
desire to do things, but to physically do them would kill him. With this understanding of
his corporeality, case 9 decides not to “take the chance.” In essence, according to case 9,
not “listening” to one’s body, or not taking one’s body into account in everyday
experience, is gambling with one’s life.

Int: Are you more body conscious now since you've had the stroke?

Par: Oh, you have to be. You don't got a choice. Like, I wouldn't walk to that mailbox
and back, ‘cause I don't know if I'll pass out at the mailbox or make it back. So,
no, there are, it's like my body is gone as far as being considered for desire, you
know. I always have a desire but the will and go out and work would kill me. So,
I wouldn't take the chance.

Int: So-

Par: I know it'd kill me.
Case 21, a participant categorized as moderately independent on overall FIM score, rated a 6 in locomotion and a 2 on stairs, notes that most days he has little energy, but there are days when he wants to do a lot. This account presented in the following extract offers a middle ground regarding the testing of physical limits. In particular, if one feels like he has little energy then he may decide not to test limits, but on days he feels like doing “a lot” the stroke survivor may push his limits more than usual. For example, on the days he has energy, case 21 will get his walker and take a walk outside “to see the sun.” The participant notes that he does this for a “little while” but tends to get overheated, needing to return home where it is cooler.

Par: Well, there are days where I wake up, the majority of times, with very little energy and other days with the urge to do a lot and well, I get the walker and walk around. I go outside for a little while to see the sun and I come in again because if it is too hot I have to enter the room again and be inside in the coolness.

Case 12, rated as completely independent on the FIM in locomotive and stair tasks, discusses the best part of his day as being the times he walks with his son and brother. The participant notes that he cannot walk the same as he used to and he tends to get tired much easier than he did prior to the stroke event. In the below extract the stroke survivor presents a moral description of his embodied self, stating that he “can’t stand up and do it right no more.” When asked if he is doing anything to make his body stronger, case 12 answers that he is just walking a little bit and using his mower. The interviewer wonders about physical therapy participation, a more professionalized approach to testing one’s physical limits. The stroke survivor, however, tests limits through participating in outside routine activities like taking walks and performing home lawn care.

Int: What are some of the things that you can't do now that you were able to do before?
Par: I can't walk. I can't walk that far to the walk. Can't do things I wanna do. I can't do it. I can't stand up and do it right no more.

Int: Since you've been home, are you doing anything specific to make your body stronger?

Par: No, not necessarily.

Int: Are you doing any exercises?

Par: Just walkin', that's all.

Int: Just walkin'?


Int: They don't have you doin' any kind of physical therapy at home?

Par: No. I use the mower.

Similarly, case 5 (completely independent in locomotive activities as rated on the FIM) describes taking morning walks as his way of staying healthy, as well as the best part of his day. As illustrated in the following extract, testing one’s limits, therefore, may differ in accordance to not only one’s sense of embodiment, but also in accordance with how one decides to, or not to, negotiate with environmental possibilities.

Int: Okay, and then what do you do after that?

Par: Well, just sit around. I don't do that much.

Int: So after you get up on Mondays, Wednesdays and Fridays, you have dialysis. What do you on the other days when you get up?

Par: Well, in the morning I generally go for a walk.

Int: Okay.

Par: Then come back to the bed; take my medicine.

Int: What do you think is the best part of the day for you?
Par: Mornings.

Int: The mornings? What makes that better?

Par: Well I'll go for a walk outside.

Int: Okay. What do you do to stay healthy?

Par: Go for walks

Cases 17 and 21 discuss how their physical interaction with the sun factors into the extent of outside activity they participate in. Case 27 (rated completely independent in locomotive activities and rated a 6 in stair mobility on the FIM) presents additional insight into how stroke survivors decide whether to go out or stay in. The participant says that there are times he thinks about going out and trying, but then concludes that would be “dumb.” At this point his wife joins the conversation, telling case 27 that he does not walk as fast as he used to, and has slowed down a lot when they go to the store. But she adds, “it’s okay.” Thus, what is a reasonable time to walk 150 feet depends on who it is that is doing the reasoning. Slowing down may not be a major functional problem in the confines of the clinic, but such a shift in locomotive activity may be problematic in the embodied experiences reflected upon in the everyday life of a stroke survivor.

Par: But I would get out there and try but then I'd think that be dumb.

wife: He doesn't walk as fast either. Like when we'd go to the store he's slowed down a lot and know it has to do with that and it's okay.

Oftentimes stroke survivors find themselves spending much more time at home than they do in public. Due to the help required to maintain balance, or the increased level of fatigue when attempting locomotive activities, stroke survivors may find going out problematic. For instance, case 2, a moderately independent stroke survivor as
classified by overall FIM score, rated a 5 (requires supervision or coaxing in walking 150 feet) in locomotion tasks, and a 4 in stair tasks, offers a pragmatic determination of whether he should go out to a specific public setting, a party, or stay at home. His decision to stay at home, however, is seen as something that is frustrating, for before the stroke he would have gone to the party and danced. As this extract shows, simply being able to walk 150 feet may not be how the stroke survivor himself measures functional independence in locomotive activity.

Int: And do you now get frustrated with things that in the past did not frustrate you?
Par: Oh yes.

Int: Like what? Give me some examples so that I can better understand.
Par: If you go to a party one would dance. Now why should I go just to sit in a chair? If I am going to sit, I might as well stay here.

Cases 28, 13, 3, 2, 12, 5, 17 and 21 are indicative of stroke survivors whose daily routines center around their locomotive activities as well as their current efforts to regain the form and magnitude of physical locomotion that they had prior to the stroke event. For many of these stroke survivors, most of whom have retained at least a large degree of their speech capabilities, limitations in locomotive capability are the most poignant effects of having a stroke. As seen in the extracts provided, walking is more than just leg movement. It also involves arm swing, balance, and energy, as well as others’ perception of one’s bodily presence in the local setting.

Case 21’s account offers a glimpse into how body, self, and world are intertwined in everyday life. Having difficulty in getting up and walking, the stroke survivor, categorized as moderately independent on overall FIM score, rated a 6 in locomotion and a 2 in stair mobility, states that he is “like half a person.” This extract, similar to an
example presented in the research conducted by Ellis-Hill et al. (2000) as discussed at the conclusion of Chapter 2 of this dissertation, seems to imply that he is able to communicate with and understand what is going on around him, but unable to physically negotiate his immediate environment the way he did prior to the stroke.

I do not feel secure. My right leg is not very steady. It is difficult to walk. To get up. I feel bad in that sense. I am like half of a person.

**Dealing with a Wheelchair**

Many of the accounts presented so far have described the enjoyment the participant experiences from taking walks outside. For those who are primarily wheelchair bound, walking often takes on even greater significance. For instance, case 10, (rated a 5 in locomotion and 1 in stair tasks on the FIM) discusses how being in a wheelchair has impacted his public activities. Like case 1, case 10 senses that he has improved, but is still not as “good” as he was prior to the stroke event. Rather than going to church three times a week, the participant indicates that he currently only goes once. As the stroke survivor reports in the following extract, it is difficult to find a mode of transportation that can accommodate his locomotive needs.

Par: I use to go to church three times a week. I'd go Sunday, Sunday night and Wednesday. But now I'm not strong enough to go all the time so, I just go on Sunday.

Int: So you're feeling?

Par: I'm just not-

Int: Just a little, not up ta-

Par: Not up ta par yet. I'm improvin' now a little, but I'm not up to that point.

Int: Okay. I'm sorry. I don't remember. Were you using the wheelchair before your stroke also?
Par: No, I was using a walker. Now I'm having to use a wheelchair so-

Int: So that's something that-

Par: But it's hard to get, for somebody to come and get me because most the cars you can't get no place for the wheelchair to get me in. You know, the trunk isn't big enough.

While some of the participants offer advice on which assistive devices they prefer to use when accomplishing locomotive activities, case 10 provides an account that illustrates the lived differences between using a walker and being in a wheelchair. As the next extract indicates, with a walker, case 10 was able to move on his own. In a wheelchair, the stroke survivor is highly dependent on others to help him move from one place to the other.

Int: Has being in the [wheelchair] changed anything compared to being in the walker?

Par: Well, I can't get up and go when I want to. Before with a walker when I wanted to go do something' I'd, like the bedroom and places, I'd get up and go. But now I have ta say, "well wheel me back to the toilet or to the ol' bedroom. So, that's a big difference. That's the only difference.

Int: So, you had more mobility and were able to move around better before your stroke?

Par: Yeah. I could move on my own. I could move on my own with a walker see. But now I have to ask somebody to wheel me.

The difference in social perception between using a walker and being in a wheelchair appears to be minimal for case 10. This may largely be because the public setting case 10 normally frequents is not a local store, but his church, where most of those who are present in the setting have known the participant for a number of years. These social others therefore, are experienced in a more intimate way in terms of interpersonal relations by the stroke survivor than are the random bodies one would experience in a public setting such as the local Wal Mart. There is even a hint of sexual identity
expressed by case 10 as he notes that “all the young girls are huggin’ my neck and all glad to see me. Makes me feel important. It feels good.” With young girls hugging the stroke survivor, being wheelchair bound while in public is not seen as representing a decrease in self-worth in relation to social others. In contrast, when cases 3, 29, and 28 go out in public, those around them either ignore them, or the help these stroke survivors receive by others in public settings simply reminds them that they are not the same as they used to be. As the following extract shows in order for the distinction between private and public settings to be meaningful, the types of relations involved in the given situation at-hand must be taken into account.

Par: I go to church and all the young girls are huggin' my neck and all glad to see me. Makes me feel important. It feels good. Hah hah hah.

Man: All that ever hug you is old women.


Int: So there's no difference in how people relate to you now than before?

Par: No, no. No, they have to see me when I come to church in it.

Int: Okay.

Par: Glad you could make it, they say. Well, glad to be here. You know.

Int: Do you ever feel that people view you differently since you had your stroke?

Par: No.

Like the other stroke survivors, case 10 sees his embodied self as getting better through time. That is, case 10 sees his future body as one that has recovered and gotten stronger than it currently is. The material measurement of recovering and getting stronger is the ability of case 10 to walk with the aid of a walker rather than his current reliance on a wheelchair. This improvement also denotes more freedom for his self.
Case 10 sees the stroke as “the breaks of life,” and indicates that he had no choice but to use a wheelchair. With this acknowledged, case 10 is looking forward to the moment when he no longer needs the chair for locomotive activities. For as he, his family, and the interviewer reiterate, case 10 “loves that walker.” As the below extract from case 10’s interview illustrates his preference for one assistive device over another is not simply a matter of comfort, but a matter of how the participant experiences his self in both private and public settings.

Par: Well I'm gonna recover and get stronger. Get back on my walker again and I'm looking forward to it.

Woman: He liked his little freedom with that walker. I can say he did like that. He always made the statement that he wouldn't get in that wheelchair until he absolutely had to.

Par: And I had to.

Woman: And he had to.

Par: And I'm lookin' forward to getting' out of it.

Woman: Now if we go out to Wild Ridge or something like that he goes in the wheelchair. Because it's too far for him to walk.

Par: I go to them concerts once in awhile.

Woman: He loves that walker. He does.

Int: He loves that walker.

Par: I like them concerts at Wild Adventures yeah.

Int: With the walker? Have you had it in your mind from the very beginning to get back in your walker?

Par: Yeah I've had it since the beginning to get back in my walker.

Woman: That's why we're going to try the-

Par: My walker over the wheelchair.
While some of the participants have expressed the importance of testing one’s limits, et al. have discussed the importance of not doing too much for safety reasons, case 10 seems to take a middle position. That is, he practices walking in the mall about once a week, using his walker. Case 10 is finding his limits by moderately testing them. He compares his self-therapy to that of the professional therapy he received initially after the stroke. Case 10’s conclusion is that the professional therapy was “too much,” and did not result in any noticeable physical improvement. In the next extract the stroke survivor details how his own therapy of walking in moderation is seen as working better for him and as something the stroke survivor will continue to do until he is completely “free” of his wheelchair.

Woman: The mall's pretty big.

Par: And as long as I practice my walkin' I get to use the walker. And I'm lookin' forward to it.

Woman: I figured we'd do that like once a week, you know, not tire him out too much and see what happens.

Par: I found out that one thing, if I do it in moderation, and don't tire myself out I do better. Because when I was down at, taking that therapy? The guy would walk me there until I was just plum out. And it didn't seem to do that much good. But it seems to do better if you do it in moderation. You know walk a little bit and... You know how long that therapy room was down there? Well, he use to make me walk all the way down to that red dot and circle that red dot and walk back. And that was a little too much. By the time I got back to the chair I would give out. And, it didn't seem to do too much good. Because I did it for two weeks you know. And it didn't seem to do too much good. But since I've been home I've been walkin' more in moderation. Been takin', not getting as tired.

Woman: A little bit further each time.

While going “a little bit further each time,” case 10’s family remains concerned about the stroke survivor falling down and injuring himself. The main concern seems to
be the energy case 10 expends while walking with his walker, and that taking it a bit further may result in him fatiguing to the point that he goes “too far” and falls down. When walking around the house, family members ensure that the wheelchair is always around, so that if needed, they can “rush it and get him.” The stroke survivor’s family members have virtually become physical therapists, helping assist case 10 in walking exercises, encouraging him to do a bit more each time, but also keeping an eye out for his safety. As indicated in the following extract, unlike the actual physical therapist who pushed case 10 “too far,” netting minimal results, case 10’s family members allow the stroke survivor to implement his own preferences regarding locomotive activities, going at a pace and distance he finds optimally desirable.

Man: We don't want him to fall.

Woman: Because he can come out of the room and come out here-

Par: Without getting' too tired see, I've been-

Woman: We had this wheelchair about yonder because if he gets weak we can rush it and get him. Because he can walk to the wheelchair. See we don't get it too far where he can get it to the door there. But he takes the walker and goes on to his bed.

Case 11, a 57 year-old stroke classified as a moderately independent stroke survivor on the overall FIM score, is rated a 2 in locomotion (maximal assistance; stroke survivor performs 25% to 49% of effort to go a minimum of 50 feet. Requires assistance from one person only) and a 1 in stair mobility (total assistance; performs less than 25% of effort or requires assistance of two people, does not go up 4-6 stairs, or is carried), is another participant who discusses the changes in his life since becoming wheelchair dependent. Due to feet and leg swelling, the participant relies on a wheelchair for locomotive activities in public settings. As case 11 states, “it’s kind of hard in the
wheelchair.” The participant and his wife then expand upon this point. His wife
discusses how it is hard for him to get around in such familiar settings as a restaurant or
bingo parlor. If he attempts to walk around without the wheelchair, he stumbles, relying
on his wife to assist him in maintaining balance. Due to shifts in locomotive ability, case
11 sits in the living hours at a time without getting up. The following extract shows the
impact such changes have had upon the person as the participant pounds his fist on the
table as he recounts how he can no longer stand up and walk to the bathroom, or go to the
kitchen to get a drink.

Int: So you get a lot of swelling in your feet and legs?

Par: Yes I do. Mostly when I travel.

Wife: And it's kind of hard in the wheelchair. Like in a restaurant or the Bingo
Hall. And it's kind of hard for him to get around in a wheelchair and it's frustratin'
to him. And then whenever he don't take the wheelchair, if he drops the ball, then
he's stumblin'. I either have to hold his arm, sitting in a chair, and go get him
something to drink or whatever. And he'll sort of sit there. Not get up. And sittin'
there 2 to 3 hours.

Int: Sitting where?

Par: Well, once I get seated and everything, ah, sittin' in there [living room] for 2 or 3
hours. I mean, it's, it's just (begins pounding the table).

Int: Hard on you?

Par: Hard on me. And I can't get use to the idea. I mean, I'm used to getting up and
goin' to the bathroom and getting my own drinks and stuff like that.

Int: You don't do those things?

Par: Well, (pauses) I can't do 'em. I mean, I say I can't, I mean, I could (laughs) if, I
uh…

Case 11’s wife discusses how these shifts in locomotion are embarrassing for her
husband. Relying on his wife for public mobility, case 11 does not wish to go out as
often. As his wife informs the interviewer, “people just stares at you.” Case 11’s body is now on public display as something that cannot function the way bodies are expected to.

The extract provided below illustrates how this social experience is seen as “embarrassing” and impacts the stroke survivor’s desire to go out into social settings.

The participant eloquently describes the changed sense of self that is experienced from this shift in locomotive ability when he states, “I’m independent. I have been all my life. I mean I’ve just been used to goin' and doin' things.” Now case 11 has to rely on family members in order to do things he would normally do on his own. The times case 11 does attempt to do things on his own, such as use a public bathroom, he is concerned with falling down, the result of which will be requiring an even greater amount of assistance than he currently does.

Wife: It's embarrasin' to him if I have to hold on to him in public and help him do everything. He don't want to be in public with me have to do every… you know, people, just stares at you. You know what I'm tryin' to say?

Par: I'm independent.

Wife: And he's very independent and that's it. It bothers him that I have to do that.

Int: So you're independent?

Par: I have been all my life. I mean I've just been used to goin' and doin' things. Like the old sayin' goes, if you don't do it yourself it ain't goin' to get done. Yeah, I've had to rely on everyone. The kids, and her, so…

Int: When you go out either shopping or restaurants what that's like for you?

Par: Well now that, and, it's more shopping. It don't bother me as bad except when I'm in a wheelchair or whatever, but um, when I'm in a restaurant, that is frustrating.

Int: ‘Cause you don't get your own drink and go to the bathroom, you said?

Par: Well, I go to the bathroom. I mean, but, you know, she can only carry me so far, and, I have to be careful of, when I'm in the bathroom, 'cause there'd be soap or
the janitor may have just got through cleaning the bathroom and the floors are wet and things like that.

Int: So you walk into the bathroom, you're afraid of falling and needing picked up?
Par: Yes, um-hmm.

Cases 10 and 11 are not the only participants to provide an account of everyday life in a wheelchair. In discussing his enjoyment for taking walks, case 26 describes how his daughter-in-law helps the stroke survivor get in and out of his wheelchair. With the interviewer mentioning that his family helps load him into the car, the participant replies, “yeah, just like packing baggage.” Using such a metaphor for one’s body seems to indicate a loss of independent functioning. Seeing the body as baggage is also a moral comment on the usefulness, or independent functional ability of one’s corporeality. That is, to state that the body’s use value is equivalent to that of a piece of luggage relegates the body to a sack that holds objects (e.g. one’s self) inside of it; a relegation that is in opposition to an understanding of the body as an active entity aiding in the meaningful construction of lived experience. While those present in the situation laugh at the statement as a joke, the participant’s utterance has important ramifications for understanding how the stroke survivor is interpreting everyday life.

Int: What are your greatest concerns about your body now?
Par: Well I like to get out and walk. I just call my daughter-in-law and that there's some place we got to go to. I go out to that place and she brings the wheelchair. And I get out of the wheelchair and she puts the wheelchair in the back. And we take off.

Wife: (laughing)

Int: (chuckles) Okay, so they load you in?
Par: Yeah, just like packing baggage.
Case 25, the 40-year-old divorce who currently lives with his mother, presents an account that differs greatly from the others in terms of how intimate family members act and react to situations in which the stroke survivor is bodily present. Although he is rated a 7 in locomotion on the FIM, indicating that he can go 150 feet in his wheelchair without any assistance, the change from walking to being wheelchair bound has dramatically impacted case 25’s everyday lived experiences. In the extracts presented thus far, the participants’ accounts have reflected upon the love and help family members have provided for the stroke survivor. In the next extract, as case 25 describes his current relationship with a sister “who I love very much,” he details how she physically reacts upon seeing him. Now wheelchair bound, the participant’s sister begins to cry when she sees her brother in such a physical condition. Further, case 25 states that his sister is not able to provide transportation help to and from the hospital because of the emotions she expresses experiencing when attempting to do so. The participant adds that his sister would like to offer such assistance to her brother but “can’t stand me in a wheelchair.” Due to such reactions, case 25 informs the interviewer, “I do things alone.” Whereas case 26’s wife and sister-in-law can laugh about such transportation situations, case 25 and his sister handle such environmental intricacies in a different manner.

Par: I got a sister who I love very much but she looked at me, she gets like all in a, you know, she gets a tear in her eyes and she can't look at me in a wheelchair

Int: Without crying?

Par: Yeah, and she can't see, so I mean she won't even take me to the VA hospital because she gets too upset. I mean she wants to but she, I know she can't stand me in a wheelchair. So I, I, I do things alone.

The problems case 25 faces in home and public settings are seen as a result of his current corporeality rather than resulting from social and environmental limitations. That
is, it is case 25’s body that is the problem, not limited access to resources or negative social perceptions. In discussing current frustrations, there is only one case 25 can think of:

…I am frustrated that I can't get out of this chair. ‘Cause I'd like to get out of it. Other than that no.

While not able to rely on his sister for help, case 25 does discuss “counting on” his friends for “so much.” This dependency on social others seems to limit case 25’s desire to go out in public, as he states “I really don’t go out that often.” Case 25 informs the interviewer in the following extract that he does not like being seen by others when he is in a wheelchair, expressing remorse that his self is wheelchair dependent. Others that do not know case 25 well ask what has happened. The stroke survivor does not want to feel obligated to constantly discuss the event. In this sense, when going out in public, not only is case 25’s body on display, but so is the stroke event, as he is asked by social others to recount what has happened to his body.

Int: When you go out in public or go shopping what's it like? What kind of things are different for you now when you go out?

Par: I really don't go out that often and when I do I tend to rely on friends to, I count on them so much. I don't like to be seen in my wheelchair. I have some remorse about being in the chair. You know, other than that…

Int: Because people look at you differently?

Par: Yeah.

Int: ‘Cause you're in a wheelchair?

Par: Yeah people that already know me look at me like… So you know… Do I have a need to yell and explain myself? No. But these people are so… I look at them and they look to me and they want some kind of explanation I don't want to give to ‘em.
When alone in his house, however, case 25 seems to be more at ease with being in his wheelchair. This conclusion is drawn when the participant, asked what he has learned to do on his own since the stroke to make his body work better, performs a “wheelie” for the interviewer. Stating that he does not have wheelie bars on his chair, he tells the interviewer that he “could do anything on these things.” The following extract shows that case 25’s lived experience in his wheelchair is highly dependent upon the social reactions that are expressed towards his body.

Par: Oh I could drive a wheelchair. I couldn't do that before like this. (participant shows interviewer a wheelchair trick) serious that I, I…

Int: Now you're doing wheelies.

Par: Now I, well I don't have wheelie bars on, but I could do anything on these things.

While one may improve in their maneuverability in using a wheelchair, there remain practical considerations such as going up and down the front steps of one’s home. In the extract presented below, case 3 describes his home adaptation for the functional limitation he experiences in trying to negotiate steps. Earlier, case 3 discussed skinning his knee while attempting to construct a ramp on his front porch. With family living only a few yards away, he has decided to direct the building, having his two grandsons, two daughters, and his wife perform the physical labor involved in the construction.

Int: Yeah, I saw the ramp, how's that working out?

Par: It's comin' along pretty good. I've got the grandsons helpin' me and the daughters and my wife. They're makin' it. I tell 'em what I need and all the things. I show 'em what I gotta do and then, they'll do it. So, pretty good kids.

Case 11, however, is not as fortunate when it comes to having family members readily available and readily capable to construct such a ramp to aid in locomotive activity. In the extract below, the participant discusses how he is attempting to negotiate
between contractors and his medical care provider in getting a ramp built so that he can get his motorized cart to the family car.

Int: And then, we also were talking there are some things that you were waiting for, like the ramp, and stuff like that?

Par: Well yeah, I've got to have a ramp. I know that the lady down in Gainesville, that's where it was established at, said that she, I called her up and I don't know, she said that the paperwork was lost. That there was no paperwork received. I said that I mailed 'em out and I did. And she said that they had, they had got lost.

Wife: And you probably won't never get it done.

Par: I've got, I mean, I can't put the scooter in the car until the ramp gets in there. And then I got the ramp on the outside in order to get it downstairs. You got to lug it upstairs.

Wife: I picked that sucker up and put it in this house and I mean it took about a week here, my back, oh Lord, I ain't lyin' it...

Par: I don't want to put a rush on or anything, but I can only get one contractor and everybody else wants their money up front, and I know that the VA don't do that. They want the money, but just one contractor said that I can do it, no problem. I said okay. So, that's the only one I got that can do it. And you just gotta have 3 estimates, and out of six people only one, they always want their money up front. And I told them that the VA doesn't operate that way. So they turned me down. They didn't turn me down, but might as well say they did.

Case 11’s wife discusses the personal burden she experiences from having to aid in her husband’s locomotive activities. Having a bad back herself, “lugging” her husband in and out of the house is physically problematic for her. The following extract shows how the ramp, therefore, is not only needed to assist the stroke survivor, but also his caregiver.

Wife: It sure would be a lot easier for me if we could get around instead of me havin' to lug him in and out of the house, especially with my back the way it is.

Int: How do you lug him in and out of the house?

Wife: Well, I mean, oh, I don't. When I say lug him-

Par: I walk down the steps and-
Wife:  I help him up and down the steps and then I have to carry the wheelchair.  This wheelchair is not that heavy, but with my, see I've got to have back surgery and everything and I've got two plastic discs and I'm not suppose to be pickin' up anything that is really heavy.  And of all times when I pull and tug on that chair, in and out the van, you know, like during the day I'm payin' bills or somethin', the next morning I can't get up.  And it's stopped for 3 or 4 days here.  I'm down on my back, by me luggin'.  But you see what I'm sayin', if we had the ramp then I wouldn't have to do all this pulling and tuggin' and it would be a lot easier on me, as well as him, because a lot of times, if I'm sick or busy and then he's wantin' to go outside he has to stay on them steps.  And then I have to quit what I'm doin'.  Gotta make sure he gets outside, and if, and if he stumbles goin' up the steps as well.  And, it will be just a whole lot easier on him, if we had the ramp to get in and out of the house by his self.

Not only would the ramp provide physical assistance to both case 11 and his wife, but as the wife explains in the below extract, it also would make the stroke survivor feel better about his self:

Int:   He could do it more or less yourself with, with the assistance of the ramp?
Wife:  And he would feel better about his self if he could do it by his self.

Other Health Problems

For case 19, a 57-year-old male, his stroke was not the initial event that led to a change in how his self was presented to others in everyday life.  Case 19 had lost his leg prior to the stroke event due to circulation problems.  So although not currently walking the way he would like, case 19 had experienced shifts in locomotive activities prior to the stroke event.  As the participant states, “this is not so much as the stroke but it goes back to all the time I spent in the hospital.”  In the following extract, case 19 describes the ordeal of getting his prosthesis and how it affected his everyday life, particularly as it relates to paid labor.  Knowing that he was going to lose his leg, case 19 talked to his employer about coming back to work after receiving his prosthesis.  It took eight months, however, and case 19’s physical strength had decreased.  These factors, not necessarily the stroke event, are linked with his current employment status.
Par: Even after I came out and knew I was getting a prosthesis I knew I could still do things. In fact, I had made, I had talked to the guy I used to work with doin' the floors. We had discussed me comin' back, you know, once I got my leg back, but I didn't expect it to take me six months, no, it took more than 6 months. It took 8 months before they got, before I got this. I didn't expect it to take that long otherwise I would've been back to work already and I wouldn't be in such bad shape as I am now, mentally and physically 'cause I think I’m really a little bit weak.

Yet, like many of the other stroke survivors presented to this point in the current section, case 19 suggests that one should find what his limits are and try to go beyond them. In providing advice to other stroke survivors, case 19 states that they will not be able to do all the things they are used to doing, and that there will always be somebody around watching them, ensuring they do not make a “mistake,” such as falling down.

Par: When I came home, let's see, after the stroke while I still wasn't walking, I would say, uh, yeah, finding what your limit, what your limitations are and that, and then tryin' to improve on it.

Int: What you'd tell them to expect that they may likely run into when they get home?

Par: Oh, that they not gonna be able to do everything they thought that they, I mean that they was accustomed to doin' before. And somebody's always gonna be sittin' there watchin'. I don't know where this is to make sure that you don't make a mistake or, I mean, to help you if you make a mistake or fall or somethin', or is it that they are expecting you to.

Case 19 also assesses his stroke as being “light.” The stroke, when compared to his prior hospitalization after leg amputation, is not seen as a major event that has changed his life. He did perform physical therapy after the stroke, seeing improvement with his arm and hands. Thus, while using a prosthesis, case 19 is able to perform most of the self-care activities on the FIM with little if any interpersonal assistance. This, however is not enough for him, as his normal functioning is framed, not within the clinical setting, but rather within the setting of paid labor. As the stroke survivor indicates in the
following extract, “things have improved,” but yet, due to his leg amputation his life is not yet back to normal.

Par: Oh, it was all good to me because before I realized that mine was so, my stroke was so, so light because I may lose, in fact, they kept tellin' me my leg was weak but it didn't feel weak because I was, cause I walked out of here on it and I walked into the clinic on it and I walked into my, well they wheeled me up to my room but I, I walked around up there for a couple of hours before I got into bed, you know, but, I mean, as far as my arm and my hands was concerned they gave me the exercise and then I went to physical therapy to make sure I did the exercise. And things improved.

The participant reflects on the loss of his leg as the experience that has made the difference between what he was and who he currently is. He sees the meaningfulness of his future life as being dependent upon how quick he is able to get back into the frame of mind that he had been in before his leg was amputated. The participant then offers an extensive, detailed narrative, not of the stroke event, but of the discussions he had with medical experts and the decision he was faced with regarding his foot, toes, and leg. Case 19 describes the onset of gangrene as the result of a “freak” event, where a small stone entered his foot, causing the foot to become infected. The participant also mentions having an ulcer that has impacted his health a great deal. Again, the following extract illustrates how other health events may complicate how one deals with living after having had a stroke.

Int: What, um, what do you think your life would be like a year from now?

Par: Well, that also depends on how quick I can get myself back, back into the frame of mind and, uh, everything that I was in before I, before I lost my leg. Because this is not so much as the stroke but it goes back to all the time I spent in the hospital.

Int: With your leg?

Par: Um-hm Well I knew I was gonna lose it. I knew I would lose it if it didn't heal. I started out with an ulcer. Actually it started out with somethin' that was like a
quarter of an inch in diameter. Two little holes. And then before it was finished it covered the whole bottom of my leg all the way down past the ankle from the knee. Practically from knee to ankle. And from the front and the whole side. It was healing very slow and I had bypass surgery in order to help it heal, but I came home and I was walkin' around. I think I worked maybe one day, one or two days, 'cause I was tryin' to take it easy. And I was driving then. And then I was walkin' one day... And then I walked down to her job where they was doin' a lot of construction. And I was walkin' in a pair of sandals and somehow the, I must've got a pebble up underneath my toe ‘cause it punctured the skin and it didn't heal.

The participant continues, describing how he watched his foot turn black and the skin peel off. At this point, case 19 made the decision to seek out medical expertise. But even with the help of experts, he experienced no improvement. Once told that a toe amputation was necessary, the participant relates how he began understanding the ordeal he was going through. The following extract from case 19’s interview illustrates how a person often must negotiate between her own understandings and medical expertise.

Par: And after I watched it turn black and the skin peel off I had went down to the clinic I think about 3 times. And it didn't get any better with everything they were putting on it so then they diagnosed it as gangrene. They decided to send me up to Bay Pines and so when I went up there I had the same doctors that I had with the ulcer. So, he came in and he looked and he said, "You know", well, he told me he was goin' to take the toe. I mean [are you going to take] this toe off and then 3 or 4 months from now I come back and you got to take another toe, and another toe, and another toe? I said, 'cause this gonna be goin' on all year. The rest of the year, the next year, and the year after. And then endin' up with a half a foot and then no foot, and since the ulcer is not healing all that well, not fast, 'cause I think the whole time from the time of the bypass to the time that I came back it had only shrank about an eighth of an inch around the sides. So I figured, we figured it was gonna take a long, long time. I figured a couple of years before it would've disappeared. So since they was gonna have to go and operate I told 'em to I said, "Well, let's just cut off the whole thing up to the top of the ulcer,,” which is what they wanted to do. One doctor wanted to do when I first came, he wanted to cut my leg.

Int: To take it off?

Par: You know, without exploring any other options.
The participant describes his bypass surgery as an effort to help him heal his ulcer that had infected his leg from below the knee to his ankle. In detailing his discussions with medical experts, case 19 brings up one doctor who had wanted to amputate the leg from the beginning. Case 19, however, saw this early suggestion to amputate as “not exploring all the options.” He then goes back and forth between losing a toe every few months, eventually having his leg amputated anyway if his ulcer did not heal, and having the amputation in the initial surgery. Although his decision mirrors that of the doctor who did not “explore any other options,” case 19’s narrative illustrates the thought process he, his wife, and those caring for him, went through prior to the surgery. This event appears to have much greater impact on the participant than does his stroke event, which he refers to as “so, so light.”

Case 19’s narrative illustrates the fact that many of the stroke survivors are people who are experiencing and dealing with a variety of health issues, such as heart failure and diabetes. For case 19, getting his “life together” and “getting back to work” are things he must work hard at accomplishing due to the amputation more than from the stroke event itself. Although the vast majority of questions asked to him are stroke related, case 19’s account continually reflects back upon his amputation surgery. Loss of limb appears to be an event that is “always there,” continually reflected upon and analyzed by the person who has undergone the experience. Case 19’s construction of his future self seems to be a self that must constantly negotiate between his past self (who he was prior to the amputation) and who he is in the present (a person who has “lost a leg”). As the next extract shows, categorizing these participants as stroke survivors may gloss over other concerns the participants state as having an impact on who and what they are.
Par: But since that's the way it looked like we were gonna there, I was gonna be comin' back every two to three months getting another toe cut off, I said well we'll just do this so I can get my life together and try and get back to work. So, that's why I waited until the next morning. I was still movin’ around. I wasn't dead. I was still breathin'. I could still get up and down and walk. So I figured it could wait.

Another example of how prior health states may impact one’s sense of self is case 23. Having been diagnosed with having arthritis of the spine, the participant’s gait had changed prior to having the stroke. One residual effect from the stroke is that he “drags” his leg. Case 23 hopes to improve his locomotive functioning so that he has a “normal stride.” The participant defines normal in terms of the way he picks up his leg and puts it back down. Case 23, a married 67-year-old who lives alone, says that his current locomotive activity “sticks out.” That is, it is abnormal, a term whose meaning is not only dependent on the stroke survivor, but also on the perception of social others. Although he previously had difficulty with walking, the stroke has added a new dimension to the problematic of everyday locomotive activity in that his leg does not function normally.

Before the stroke, case 23’s locomotion was hampered by aches and pains. Now, not only must he negotiate with a painful body, but he must also negotiate with a leg that will not lift up and go back down the way a normal leg should. Rated in locomotion and stair mobility as modified independent, the following extract indicates some of the backstage work that must be done in order for the participant to walk, as well as how the participant negotiates between normal and abnormal body conception.

Par: When I came in the problem was arthritis of the spine so I'd been having problems walking or moving about and certain times of the day or night or evening or whatever.

Int: That was before your stroke too?
Par: Oh that was way before the stroke. I'm dragging my leg... but I wait till you gonna get... you gonna get to that?

Int: (chuckles) Well I mean do you have any concerns? What are your greatest concerns about your body now?

Par: Well I just want to be able to walk with a normal stride. You know, other than that I'm fine.

Int: Right, I'm fine. So you don't find that you really focus on your body more than you did before?

Par: I do because it, it, it stands out.

Int: Your leg?

Par: I can't walk uh, normally. By normally I'm talking about the way that I-

Int: Pick it up and-

Par: Pick it up and put it back down.

This chapter has presented a variety of accounts from people who are negotiating the meanings of everyday embodied experience. Body, self, and world are made meaningful in relation to how these stroke survivors interpret physiological changes (specifically to this chapter are changes in locomotive functioning), changes in everyday routine practices such as going shopping, going to church, or dancing at a party, and changes in how social others perceive the stroke survivor when involved in face-to-face encounters. Chapters 5, 6, and 7 can be seen as offering a detailed account of what Holstein and Gubrium (2000) refer to as the working horizons of identity. Certainly the interviewing experience itself helps to construct the immediate identity of stroke survivor. Still, as the participants begin to reflect upon their local experiences, certain stories emerge.
Regarding locomotive activities, getting back to normal, testing one’s limits, taking it easy, maneuvering in public settings, the perception of one’s body by others, and familial care, are all major themes, or signposts, found in the accounts of stroke survivors. The particular way these signposts intersect, or play out, for any given stroke survivor is dependent upon how the participant narratively links such everyday local concerns. That is, as the stroke survivor provides his account of everyday lived experience, he also actively constructs the self he lives by.

Self-control is, in part, shaped by how predictable one’s bodily performance will be (Frank 1991). As Frank (p. 51) stated, “we may know what we wan the body to do, but ‘it’ retains some contingent will of ‘its’ own.” Frank relates this contingency to George Herbert Mead’s notion of the “I”. One gets things done through bodily interaction with the environment. When physical predictability decreases, bodily slips, such as falling down or swaying to and fro while walking, become more frequent. With a less predictable I, one’s social self, or “me” is experienced in a less favorable light. Due to such lack of bodily control, some like case 9 become more embarrassed with their social selves. After stroke, the body lacks discipline. One’s regiment, or daily routine, is impacted due to physical limitations.

Through face-to-face communication the stroke survivor may feel that their social recognition has changed, often from one of an independent person to one who is dependent on others to function normally. The body is found to be lacking, requiring either assistance from a device or person in order for the stroke survivor to perform his normal routine activities. These physical limitations are linked not only to a greater lack of control and predictability, but also with a decrease in self-desirability. That is, stroke
survivors may see their selves as less attractive socially. This is reflected in accounts of how others may ignore them in public, how food may dangle from one’s chin, or others may burst into tears upon seeing them in a wheelchair.
CHAPTER 8
ROUTINE ACTIVITIES

Prior to discussing how the stroke survivors’ accounts relate to the FIM and FAI analysis, and how stroke assessment is often an interplay of a variety of discourses, forming a local discourse-in-practice that takes into account not only medical and everyday understandings, but also the environment at-hand and biographical information, the routine activities that the stroke survivors reflect upon are presented. Whereas eating, bathroom and dressing work, and locomotive activities relate specifically to motor items found in the FIM, the routine activities addressed in this chapter relate more specifically to activities that go beyond self-care practices. First presented are activities done at or around the home. After these routine activities are outlined, activities done away from the home are presented. While not exhaustive, this chapter is designed to illustrate some of the major everyday activities that permeate lived experience for a variety of stroke survivors such as cooking and watching television, as well as providing a few examples of specific activities that are meaningful to only a select few of the participants. That is, there are some activities that we all do, and other activities that are meaningful to us but not to others (hobbies).

Meal Preparation

Preparing meals is an item included in the FAI, a scale designed to measure lifestyle activities that go beyond the self-care tasks measured by the FIM. Cooking food, however, is often an intimate aspect to eating. For instance, much food requires some kind of preparation prior to bodily ingestion. Therefore, cooking is often an
important aspect to self-care. If one cannot prepare meals then he must greatly limit his diet, eat out for all his meals, and/or rely upon others to prepare meals for him at home. While this may be more of a concern for those categorized as moderately independent, there are highly independent participants who also discuss the importance of cooking in daily life. For example, case 3, a married 67 year-old non-Hispanic white with a high school education and annual income between $15,000 and $25,000, relates the everyday routine tasks performed by his wife, eventually telling the interviewer that without his wife he’d be in a nursing home. Even those stroke survivors who can utilize a fork and chew food often have a difficult time doing so without someone there to prepare the food and set it up for them so that the only things they do independently are the basic tasks measured by the FIM. In the short extract presented below, the interviewer asks case 3 how his wife, who case 3 states is with him “24 hours a day, seventeen days a week,” helps him out in daily life.

Par: Sometimes like that carries all my food to me, makes me eat it, so I'm, I'm usually pretty good appetite.

Int: Um-hmm (both laugh)

Par: She does all the cookin', housecleanin', everything else here. She's the backbone.

Int: Um-hmm. Does she help you out in the afternoons in any specific way?

Par: Oh, yeah.

Int: You said she makes the lunch?

Par: Oh, yeah, she makes all, does all the cookin'… So, so I say it's somethin' goin' on constantly, she's doin'.

Without his wife, case 3 would most likely not be able to live “independently.” Although the participant realizes this, he does not appear overly concerned by it, for his
wife is described as an integral part of who he is (the backbone). She is always with him, and has always been with him throughout adulthood. In daily life, case 3 does not think of his self independent from his wife. The powerful metaphor of describing his wife as the “backbone” seems to convey the experience of self, where without his wife present the participant would no longer be who he is in terms of how the participant experiences his lived self as an embodied entity. While, like most of us, he routinely takes his backbone as a given component of who he is, when directly asked about the importance of having his wife with him, case 3 tells the interviewer that he realizes without her he would not be able to function at home. Looking at his factor scores on the FAI, case 3 is categorized as minimally active in domestic chores, never helping in meal preparation, washing dishes or clothes, or doing light housework.

When asked if she has difficulty performing such activities as cooking and cleaning for her husband, case 3’s wife responds nah, she’s been doing it for 40 years. Therefore cooking and household cleaning are not given much attention now, just like they were not given much attention in the decades before the stroke. Case 3 is representative of the group of participants who do not participate in domestic chores since their stroke, and in fact hadn’t participated in such activities prior to their stroke event. This traditional lifestyle may help to minimize the sense of functional loss for such stroke survivors in that some of the tasks they can no longer perform were never part of their activities of daily living, hence unimportant for all practical purposes. As the next extract shows, in terms of meaningful daily life, cooking and cleaning are often unimportant as long as their “backbone,” be it their wife, mother, or sibling, remains able to perform such routine duties for them.
Int: You said your wife is the backbone. What does that mean to you?

Par: (chuckling) Hell, if I didn't have her I'd be in a nursin' home. Let's face it. She does everything.

Another highly independent respondent categorized as minimally active in domestic chores, case 5 (married 57 year-old African-American with a high school education and annual income less than $15,000), also describes cooking and preparing meals as central tasks his wife performs for him, adding, “anything I need, she gets it.” This statement follows case 3’s description of his wife as the “backbone” in the performance of many routine household activities. The extensive level of caregiving being performed, however, may not be seen as a burden after the stroke if such matrimonial relationship dynamics have been historically performed. As the extract below illustrates, those who have lifestyles that follow traditional family activities where the man works outside of the home and the woman works inside of the home for the majority of their adult lives, may not see the man’s inability to perform certain household functions such as cooking and cleaning as being of much functional importance to the experience of stroke recovery. Case 5 knows he is unable to fix his own food, but he rarely did this prior to his stroke, and thus the impact this limitation has on him in his daily life is minimal.

Int: Okay. And is there anyone at home with you in the morning?

Par: My wife.

Int: Okay. And does she help you out in any way?

Par: Yes.

Int: What does she do?

Par: Well, she cooks me breakfast and anything I need, she gets it.
Int: Okay. What kind of help do you need from others since you've had the stroke?
Par: Well, fixin' my own food, um-hmm.

Cases 3 and 5 represent stroke survivors categorized by the FIM as highly independent and through their narratives are found to have traditionally relied upon their wives to perform household activities such as preparing meals. Thus, thanks to their spouse, not being able to cook and clean from day-to-day seems to have a limited impact on the survivor’s embodied self. Another example, case 26, uses a bit of humor when informing the interviewer of his inabilities to perform household tasks. Utilizing the FIM and FAI measures, case 26 is a moderately independent, minimally active in domestic chores stroke survivor. As indicated by the FIM case 26 (married 83 year-old non-Hispanic white college graduate with annual income between $25,001 and $35,000) is a bit more limited in mobility and transferring than are cases 3 and 5. These self-care factors limit what case 26 can do around the house, but rather than describing these limitations negatively, he tells the interviewer of how his wife routinely serves him “breakfast in bed.” Similar to cases 3 and 5, needing such assistance in preparing and cooking food may not trouble case 26 much, for his wife has always been there to perform these household activities. The next extract shows that the presence of a functional spouse affords him the luxury to have breakfast in bed and read the paper throughout the early part of the day.

Int: Does your wife help you get ready?
Par: Uhh I have breakfast in bed.

(wife laughs)

Par: (laughs) She brings the breakfast to me and I got a hospital bed.
Int: Yeah.

Par: … and the table slides toward the bed and so I eat breakfast and read the paper.

With the aid of his wife and specialized bed, case 26 manages his everyday embodied experiences in such a way that he can discuss them with a degree of humor, laughing at what others may see as important functional limitations. This sense of humor about the limitations of his body may enable case 26 to maintain relative consistency in terms of his embodied self before and after stroke. While cognitively aware of his impairments, case 26 may see them not being of major consequence to who he is, at least as long as his wife is there to aid in the important daily activities he would not be able to perform without her. For these cases, their wives are integral components of their lived selves. In the following extract another moderately independent, minimally active in domestic chores stroke survivor, case 11 (married 57 year-old non-Hispanic white with a high school diploma and annual income between $25,001 and $35,000) discusses one difference between the hospital and the home; the quality of cooking. This time, however, the participant’s wife initiates a sense of humor to the difference in food quality as the reason why case 11 doesn’t want to go back to the hospital.

Int: Just in general you don't want to go?

Par: I've had my fill in two years, cause I think this must be (laughs) 'cause I haven't had-

Wife: Chicken's not as good there, is it?

Par: Huh?

Wife: The chicken's not as good there, is it?

Par: Well, no (laughs) not as good as the wife's cookin'.
The next extract provided by case 11 offers a poignant example of how attempting certain routine activities, such as making a sandwich, helps to redefine one’s sense of self, at least in terms of functional independence. Through testing what he can and cannot do, case 11 says that he’s learned he can do almost anything. Below he describes one thing he can’t do, prepare food, discovered when trying to spread mayonnaise on a slice of bread. He tells of how he wants to pour his own milk, but spills it and makes a mess. While he still has the desire to succeed, his body doesn’t cooperate with such desires, so ultimately he “gave up the idea.” Rather than crying over the spilled milk, however, case 11 states he cleaned it up, and now appears reserved to having his wife or other family member help him in such routine activities. Unlike cases 3, 5, and 26, case 11 seems to still be negotiating the practical understandings of his embodied self, where others such as his wife and granddaughter have become important aspects to who and what he is as a physically functioning entity. The following extract shows how case 11’s body has dys-appeared, and his material body is now the primary mediating feature of his everyday life. His mind as the mediator between his self and everyday lived situations is still strong (has the desire for independence), but the body as mediator lets his self down in certain instances, such as when he attempts to cook, make a sandwich or pour milk.

Int: When people come home from the hospital they don't always know what they can and can't do. Um, how have you learned about what you can do now?

Par: (laughs) uh, well, I've learned that I can do just about anything except there's, uh, some things that I can't do and, um, I, uh,

Int: How do you, how do you discover what you could and couldn't do?

Par: Well, say for instance, uh, if I wanted to make myself a sandwich or cook. If I wanted to cook, I, I can't, you know, because of my hand and everything, I can't get it just right, and um, so I don't bother with cookin'. And, makin' a sandwich, it, I can't do everything with, with just this one hand. I tried, uh, spreadin'
mayonnaise and mustard, um, I overdo it and make a mess and stuff like that. So, I have her to make my sandwiches, and um, and do the cookin'. And, I have tried to pour myself milk a couple of times. One time I, I had the half-and-half on the, had the glass sittin' up there and had to do like that and the half of it has gone over the counter and the other half was in the glass, so, I have that idea.

Int: So, you would spill things and,

Par: Um-hmm. Yeah.

Int: So you learned that maybe some of those things you could do, you couldn't do anymore?

Par: Well, I want to do 'em but I can't. I mean, er, I say I can't but I wanna, uh, try to, like pourin' a glass of milk, I, I wanna pour it myself and then, with holdin' the glass, got the pitcher up here like this, and you missin' the hole and stuff like that, ah, I just gave up the idea of messin' with my milk and…

Int: How did you feel when you first started to do that and you noticed that you spilled some?

Par: Well, (laughs) I got me a rag and cleaned it up (all laugh).

Up to this point in the current section, the cases presented, be they highly or moderately independent, are able to live relatively normal lives in terms of their everyday functioning. This ability, however, is thanks in large part to their spouse. Except for case 11, by and large this dependence on their spouse for the performance of meal preparation and cooking seems to not have a dramatic impact on the respondent’s sense of self, with case 11 still negotiating with his changing embodied experiences. Case 10, a moderately independent, minimally active in domestic chores stroke survivor, unfortunately no longer has his wife to perform such routine activities for him. What is fortunate for case 10 (widowed 79 year-old non-Hispanic white with some college or technical school and annual income less than $15,000) is that his sister Jan lives with him. For all, or at least most, practical purposes case 10’s sister handles the cooking and cleaning, fulfilling the traditional woman’s activities that his wife had fulfilled when she was alive. Differing
from the other cases presented in this section up to the present point is that the woman performing the traditional household duties is not completely oriented to traditional female activities in daily life. She is currently employed outside the home, working all night. This seemingly places a great deal of burden on Jan, but as case 10 informs, other family members are there take care of him while Jan is sleeping. She’s up by lunch, however, to prepare case 10’s meal.

Int: Okay. What happens when, you get up and drink coffee. What's your mornings like usually?

Par: Um, I usually eat cereal. Cereal or hotcakes.

Int: Okay.

Par: Whatever I want. And after that I listen to the news, see what's going on in the world and continue to drink coffee during all the morning.

Int: Listen to the news and drink coffee all day?

Par: Yeah. Yeah.

Int: And who's usually with you in the morning in the house?

Par: Ah, my sister's usually with me. Jan gets up and joins me.

Int: So you're not alone.

Par: No, I'm not alone. Never alone.

Int: Okay.

Par: And there's always somebody with me.

Int: Always somebody with ya.

Par: And Jan works all night so, that's the truth, so she gets up sometimes in the morning. Ah, just coming in in the morning.

Int: And how about lunchtime? Do you usually eat a good lunch?

Par: Yeah, I have a good lunch. A sandwich or whatever I want.
And who usually fixes lunch for you?
Jan fixes it for me.
A salad.
Yeah. A salad?
A salad. Whatever I want, you know.
Yeah.
And-
Whatever he feels like eatin'.
Whatever you feel like eatin'?
Uh-uh.
Like most of the other participants presented up to this point, assistance in cooking and cleaning does not seem to impact case 10’s sense of self. He has family members, primarily his sister Jan, there to assist him. His connection to the world is assisted through news programming, with additional personal enjoyment gained by drinking coffee in the day, switching to “sweet” tea at night, and being able to eat whatever he wants to eat. With good beverages, self determination in meal selection, and constant companionship, case 10’s physical limitations do not seem to be of much practical concern in his daily experiences.
Case 31, however, offers a different perspective, having moved into his eldest son’s home after the stroke event. Prior to his stroke, case 31 “did not bother anyone.” He was a professional fisherman who was able to “make ends meet,” living independently with his youngest son. Now with mobility difficult, case 31 is less independent, which seemingly does have a negative impact on his sense of self. While no longer living with
his youngest son is a primary concern, there are other concerns case 31 relates to the active participation in mundane activities. Case 31, the interviewer, and case 31’s daughter Nina, discuss the impact the loss of independence in such things as cooking has had on his everyday life. As the following extract illustrates, being minimally active in domestic chores is a change in lifestyle that case 31 finds problematic in everyday life.

Int: Hmm. And is there anything else that you would like to tell me about your life right now? Anything that you would like to add because now we will look a bit into the past, before your stroke.

Par: I would like to improve, improve from this leg.

Int: Hmm

Par: If I walk, it is difficult. I want to get better so I can go out like I used to before. I used to go everywhere, fishing. I used to make ends meet.

Int: You felt more independent

Par: Yes, more independent

Int: So, you miss that a little bit, ah?

Par: I did not bother anyone. I do not like to depend on anybody.

Int: I understand.

Par: I like to cook what I like, and also do it for my son.

Nina: He brought him here because he used to take care of old people. He knows. . .

Int: How to take care of them

Nina: No, how nursing homes are, and he did not want him there.

Int: Okay.

Nina: He said "no, I rather take care of him, so he doesn't suffer.” He says that in nursing homes people abuse the elders. So he says "no".
While case 31’s eldest son has made the decision to “take care of” the participant due to the son’s experiences with and understandings of nursing homes, rather than such familial care having a positive impact on case 31’s sense of self, or at least helping case 31 continue to experience his embodied self as unproblematic in everyday life like it generally has for the other participants discussed so far in this section, case 31’s dysappearing body is seen by him to indicate that he no longer is who and what he was before the stroke. He no longer fishes the way he did, he doesn’t cook for his children anymore, and no longer lives as the caregiver of his son, but rather is cared for by one of his other children. Due to the stroke event, his body has come to intimately shape his subjectivity. Case 31 is now experiencing a different life-world, one where he is dependent on others for certain routine daily activities that he had independently performed throughout most of his life. While this can also be said for case 11, case 31 has the additional change of being the caregiver of his offspring to now being cared for by his son.

This immediate, day-to-day change in the interactional context of the home represents an important difference in case 31’s home life experiences before the stroke. Although case 11 may have mobility and dexterity concerns he did not have before, with co-morbidities like diabetes and gang green, the shift in independence has been a more gradual experience of embodiment in comparison to case 31. That is, the lived experience of losing functional ability is altered by the different health experiences faced by people prior to the stroke event. Stroke survivors bring their biographies with them, and these biographies will differ in important ways. At different points in their narration
the participants may reflect on past eating and drinking habits, former occupations and significant roles, traditional home life, or on long-term illness or health deterioration.

Case 25’s extract represents another participant who has seemingly experienced a negative impact to his embodied self by the loss of independence in daily household activities he routinely performed prior to the stroke event. He currently is minimally active in domestic chores that he previously did when living alone before the stroke. A divorced 40 year-old non-Hispanic white college graduate with an annual income between $15,001 and $25,000, case 25’s mother now does the household activities he had previously taken care of for himself.

Case 25 also represents one of the very few cases included in this study who did not return home immediately after hospital discharge, spending about a week at an assisted living facility. In discussing what his mother does for him (cooking and cleaning) the interviewer finds this to be “nice,” while the participant expresses a different viewpoint, stating that his mother drives him nuts. Case 25 wonders why it is that if he wants breakfast he is expected to wait for his mother to wake up. Although having lived in different situations before the stroke, much like case 31, for case 25 things such as cooking, which he routinely did for himself prior to having the stroke, are now activities others, specifically his mother, routinely perform for him.

Par: I went to the nursing home and umm for a little while anyways.
Int: And how long were you there?
Par: Maybe a week
Int: A week? Oh okay and now you’re home right now with your mom?
Par: Right.
Int: And she helps you?
Par: Right. She helps me. Well she feeds me.
Int: Okay
Par: And she…
Int: She cooks and cleans?
Par: Yeah she cleans.
Int: That's nice.
Par: Yeah.
Int: (chuckles)
Par: But she drives everyone nuts. She drives me nuts.
Int: Yeah.
Par: Yeah.
Int: It's hard.
Par: Cause I would just, I was married.
Int: Uh-uh
Par: And I was with myself.
Int: Right.
Par: You know I was by myself.
Int: It's tough.
Par: Whatever. Oh gosh she treats me like a ten-year-old!
Int: She's constantly watching over you making sure you’re okay?
Par: She's constantly, and she says why don't you wait for me to get up and do it? Sometimes I get up early.
Int: Yeah.
And I might have, I want, I'll have cereal or something. I can't cook.

Right.

You know things that will burn. I put the milk in the bowl and she'll get mad. Why should I wait for her?

For case 25, relying on his mother to prepare food for him is seen as a major hassle in his everyday lived experience. This extract, while dealing with the mundane activity of fixing breakfast, offers insight into how some stroke survivors must begin to deal with a new embodied personhood. At age 40 and divorced, case 25 may also be experiencing his living with and depending upon his mother as problematic to who and what he was only a few months ago. Meal preparation is an example case 25 offers the interviewer in expressing differences in his perceived sense of self that reflects upon past embodied experiences, and his current everyday lived self that is dependent on others to perform mundane tasks for him.

While acknowledging that he can’t cook things that might burn, he doesn’t see why he shouldn’t independently prepare meals that do not require such cooking techniques. This time, the negotiation of what the stroke survivor can and cannot do in terms of meal preparation seems to be continually negotiated between caregiver and the participant. Case 25 seems to indicate that such negotiations do not end up the way he would like, concluding that his caregiver drives everyone nuts due to her constant monitoring of his everyday activities.

Another example of the importance cooking had in the survivor’s life before the stroke is provided by case 16 (married, 64 year-old African American with some college or technical school and annual income less than $15,000) who frequently prepared his
own meals prior to the stroke event, but currently is unable to do such tasks. Not having had his wife prepare all meals for him in life before the stroke, the reliance upon her now is seen as a hindrance to independence. The experiences of 31, 25, and 16 differ from those who adhered to a traditional household dynamic (knowledge that signified functional identities of husband and wife at home). Now due to bodily concerns (participant’s body mediates what he can and cannot do in the practical activities involved in everyday life) they feel that they have no choice but to have their spouse or family member perform routine household activities that they may prefer to do independently. Having enjoyed preparing meals prior to their stroke, for cases 31, 25, and 16 no longer being able to do so makes their body dys-appear in their daily life-worlds.

Whereas dietary control is often shifted to one that closely adheres to medical discourse, eating as it relates to the active practice of preparing food often shifts to having family members do it for them. Although dietary control is an action adhering to a knowledge institutionally created by others, stroke survivors often see such dietary practices as a positive act of self-will. That is, through such adherence they are helping their embodied selves. In relation to preparing meals, however, the actual cooking and preparing of food is seen as a more physical activity than is the act of putting a fork to one’s mouth, at least for these participants who are functionally independent in most routine practices. If family members had control in meal preparation before the participant’s stroke, then not being able to prepare meals currently may have little impact on the stroke survivor’s sense of embodiment. If such control in cooking food was an aspect of the embodied self prior to the stroke, however, then the loss of this control is
more likely to impact one’s sense of who and what he is in his current lived experience. If one must rely on others to prepare meals for him, then the kind of food that is being prepared may not always be what the stroke survivor would have prepared for himself. If the stroke survivor fails to regulate his diet “independently,” then those preparing meals for him may exercise such dietary control “for his own good.” This independence in cooking as it relates to eating what one wants to eat is conveyed by case 16 in the following extract:

Int: Would you make your own meals?

Par: Um-hm.

Int: Okay.

Par: And I'd love because, (laugh) I could eat what I want to eat not, "what are you eatin'? You can't eat that!" (laughs)

Where case 16 may no longer eat certain foods not because of his dietary will, but because he relies on others to cook for him, case 4 is able to eat what he wants because he is able to cook what he wants, without assistance from others. Case 4, representative of those participants who remain very active in domestic chores, physically demonstrates such activity as he cooks chili during the interview. If he’s in the mood for chili, case 4 does not need to rely on others to be around and readily available and willing to prepare it for him. He simply makes it himself, at his own leisure.

Wife: Did you turn it off? He's cookin'.

Int: Ah…

Par: Chili, um (laughs).

In the previous extracts of traditional family oriented stroke survivors, those who had spouses present to care for them also historically adhered to the traditional male as
breadwinner ideology. In recent decades, such a uni-dimensional understanding to employment activity has been fragmented, as showcased by such female caregivers as case 10’s sister Jan. Although times may change, this does not mean all aspects of traditional family ideology get replaced by late modern family discourse. As seen in the extract from case 10’s narrative, although the woman works outside of the home while the man stays at home, the woman is still seen as the one who prepares all the meals. Another instance of such interplay between late modern employment practices and traditional household duties is case 8. Even though case 8 (married 65 year-old African American with some college or technical school, income not provided), informs the interviewer that he is still independent, the expression of this independence does not necessarily take into account the ability to cook.

In the domestic chores factor of the FAI, case 8 is categorized as very active, but specifically regarding the preparing of meals he reports doing so less than once a week. Case 8 represents an intriguing instance where he is relatively inactive in meal preparation while very active in other domestic chores. In this case, although the wife is now the one who works outside the home while the husband stays predominantly in the home, the traditional discourse that portrays cooking meals as the wife’s job remains the discourse in domestic practice. As stated by the participant, when his wife comes home she relaxes for an hour or so, and then “has to get in the kitchen to cook supper.” Such responsibilities appear to be a taken-for-granted aspect of home life. When the interviewer asks the participant if his wife helps him out in anyway before she goes to work, he has a hard time thinking of anything. The interviewer then prompts the participant about his mentioning that his wife prepares breakfast, suggesting that such an
activity may be considered “helping out.” With the preparing of meals now framed in
such a manner, the participant is able to discuss his wife’s household practices.

Int: Okay, and then when your wife is here before she goes to work, does she help out
in any way?

Par: Ah…

Int: You mentioned she makes breakfast for you?

Par: She, yeah she cooks breakfast.

Int: Does she need to help you with anything else?

Par: No.

Int: Okay. And what about during lunch and in the afternoon?

Par: During, during lunch I'm here, and I, ah, she has already prepared, you know,
some sandwiches and things. What I do, I have to do is put them in the
microwave, you know, for my lunch. I, ah, take my glucose. I have my glucose,
and I take it at noontime and I eat my lunch, and then it's the afternoon. Then I
get on the computer.

Int: Okay. And, what does she do, um, in the afternoons that, to help
you? Does she need to do things then?

Par: Mm, uh, no, she doesn't.

Int: Okay.

Par: I'm still independent.

Int: Okay. And then what about in the evenings? What do you usually do in the
evenings?

Par: In the evening time?

Int: Um-hmm.

Par: I uh, I'm back on the computer.

Int: (Laughs) Sounds like you like the computer.
Par: See, I was, that's right. I have, I love it. And, ah, I'm back on the computer and she comes in from work and she relaxes for an hour or so then she has to get in the kitchen to cook supper.

Int: Um-hmm.

Par: And I eat supper and then take my medication, and, um, back on the computer (laughs).

In some ways case 29 is similar to case 8. Both participants are in the very active category in the FAI domestic chores factor. Both of them also make clear statements regarding still being independent. In both households it is the women who work outside of the home, while the male stroke survivors stay at home. However, where in case 8’s home the cooking responsibilities seem to be unquestioningly placed solely upon the wife, in case 29’s home the participant talks about always preparing his own lunch, sometimes cooking dinner before the women return from work, while other times, apparently more often than not, the women, particularly the participant’s wife, cook dinner upon returning home. This meal preparation is not seen as assisting the stroke survivor in any way, at least as the survivor himself reflects upon his lived experiences. For both participants their independence is an important aspect to who and what they are. Whether or not they prepare meals, or are always physically capable of doing so in all circumstances, is not seen as problematic in their everyday lives.

Int: Okay, is there any one at home with you in the mornings?

Par: My two daughters and my wife.

Int: And your wife?

Par: Then they go to work.

Int: Do they help you out in any way?

Par: No.
Int: No?

Par: I do my own thing.

Int: You do your own thing? And how about lunch in the afternoon?

Par: I fix it myself every time.

Int: Because you are…

Par: I am very independent.

Int: You are independent.

Par: Always been.

Int: Uh-uh, umm is there anyone at home with you in the afternoon?

Par: After four o'clock.

Int: After four o'clock. But you are still doing pretty much your own thing?

Par: Right. They cook. My wife cooks once she comes home from work. Sometimes I cook before they get here.

Case 17 is also similar to cases 8 and 29 in their expressed importance of maintaining independence. Unlike case 8, however, for case 17, such independence is directly related to such mundane household tasks as cooking and ironing. When asked if there are any things he is frustrated by since having the stroke, case 17 answers “no, because I still go in the kitchen and cook.” Whatever his wife can do at home he can do. This expresses the notion that he and his wife have switched familial responsibilities. With the stroke survivor no longer working outside of the home, he has assumed the household duties, or at least as much of them as he can physically accomplish. The wife, on the other hand, is now the bread winner. In the next extract case 17 uses the rocking chair his wife recently got for him as the material expression of his loss of mobility and physical activity. While no longer employed outside of the home case 17 informs the
interviewer that the rocking chair is “not me.” At this point, case 17 is going to keep trying, even though the tasks he may be trying to accomplish have shifted from ones primarily existing in the public environment to ones existing within his domicile.

Par: Once I get up and start walking around I have no difficulty. I cook my own breakfast and I move around, do what I basically want to do.

Int: Do you make your own lunch?

Par: I make, uh-huh. Yes. Any clothing that my wife has left, I wash them and fold them and put them away. And, anything that I can do, sometimes I'll even cook dinner, so that she'll have dinner when she comes home.

Int: Are there other things that you get frustrated by, since you've had the stroke?

Par: No, because I still go in the kitchen and cook. I can fix food for myself, I can iron, wash, anything that my wife can do in the house I can do. Ah, except I'm, I'm not as strong, I know that my strength has decayed greatly, and um, cause I don't let her know everything because, you know, (laughs) I don't want her, I don't want her to be completely, in other words, I don't want to become completely debilitated in my thinking. I don't want, I'm not gonna think, even if I know that I can't do something I'm gonna try, I'm gonna still try to do it whether I can do it or not. When I can't do it, I'll tell myself, "well, buddy, you can't do it. You'll have to give it up." But, um, but I don't want to consider this rockin' chair that my wife got me, that it came in just in time here, you know? I don't want to completely become sedentary to a rocking chair. That's not me.

While differing in whether or not cooking as a practical activity is important in their sense of embodiment, the cases presented to this point have all expressed meal preparation in general terms such as breakfast, lunch, and dinner. Case 25 may be the one caveat to this, indicating that if his mother would allow him to, he could prepare such basic meals as cereal. The extract presented from case 25’s narrative illustrates that whether or not one is capable of cooking is directly expressed as being dependent upon the type of cooking being done. Another example is provided by case 22. While very active in domestic chores, case 22 informs the interviewer that his son frequently cooks for him, but that the participant does cook sometimes. The interviewer finds the
participant’s cooking activity “nice.” Case 22 then informs the interviewer that, similar to case 25, he doesn’t like to “play with the stove.” As illustrated by the extract below, whether or not the participant prepares meals is dependent upon the style of cooking being done. If the meal preparation requires “playing with the stove,” then case 22 refrains from the activity, deferring such tasks to his child. Therefore, while very active in domestic chores case 22 has made practical adjustments in how specific household activities get accomplished. Without others in the household, case 22 relies upon his son to share in the preparation of hot meals, particularly when a stove is involved in the preparation technique.

Int: He doesn't come and help you?
Par: Well I have nothing to… Do you mean cooking?
Int: Yeah.
Par: He'll cook and sometimes twice I made dinner.
Int: Oh that's nice.
Par: I was able to umm you know I don't like to play with the stove.
Int: Yeah.
Par: But twice I made dinner so uhh…

Like cases 25 and 22, case 6 also discusses the specifics of what he can and cannot do in relation to meal preparation. Case 6, another participant that is very active in domestic chores, discusses enjoying life when his neighborhood friend feeds him. He says that either she’ll cook or the two of them will go out to eat, which they have been doing more frequently recently. His friend, Norma, then adds that case 6 does cook for the two of them sometimes. When case 6 states that he can boil water and fry eggs, using
this statement as a humorous expression of his limitations in meal preparation, Norma rejects the accuracy of this information, telling the participant that he can do more than he is suggesting to the interviewer he can do.

Int: What are some of the most enjoyable things?
Par: When she feeds me.

Int: (laughs) What she, I mean when you say she feeds you, what do you mean? When she cooks for you?

Par: Well, either that or we go out and eat together, and, uh, we've been going out eating quite a bit lately.

Norma: Sometimes he cooks too.

Par: Yeah, I cook too. I can boil water and fry eggs, see?

Norma: You do more than that.

While cases 22, 28, and 6 all live alone, case 6 has a close relationship with a friend that helps him in his everyday domestic chores such as cooking. Case 6 expresses this friendly assistance in meal preparation and companionship while eating as one of the aspects to everyday life he receives the most enjoyment from. With his wife in a nursing home for the past ten years, case 6 has made other interpersonal bonds in his local community, creating a relationship dyad with a female neighbor, who is widowed, where each assists the other in activities of daily living. During unrecorded conversation case 6 informed the interviewer that he was very lucky to have this type of relationship with Norma, because all the single guys in the neighborhood were trying to gain such interpersonal favors. Norma stated this was not true, but case 6 again insisted that indeed this was the case. So he is very grateful.
As a divorcee, case 22 has created a close bond with his son that serves relatively the same purpose in terms of meal preparation, where the son frequently comes over and cooks for his father. Another divorcee, case 28, relies on male friends for such practical caregiving concerns. This particular male to male style of caregiving appears to be much more loose, with the stroke survivor himself needing to perform many practical household activities in order for them to get accomplished. In terms of meal preparation this caregiving style does seem to limit case 28’s dietary staple. Breakfast appears to offer the most variety in style of meal preparation with case 28 normally eating oatmeal or cereal, but noted that he may cook up some grits and eggs if he desires. Already prepared frozen meals are the staple for lunch and dinner.

While the implementation of a dietary will that adheres to medical knowledge helps to shape the stroke survivor’s eating practices, the presence or absence of others in the environment ready and willing to prepare the food also impacts routine food consumption patterns. In the example of case 28 one may also notice, however, that the type of frozen meals ingested follows a specific dietary regimen (Healthy Choice), illustrating an interesting interplay between dietary will and meal preparation. Interestingly, the mornings seem to offer a looser style of diet where eggs and coffee are commonly consumed, while lunch and dinner offer more strict consumption patterns. These routine practices in eating and cooking may also be impacted by the survivor’s energy level and stamina, with the stroke survivor’s ability to cook a wider variety of food greatest in the morning, tapering off in the afternoon and evening as his energy level and stamina decrease.

Par: And I come out the shower and I go into the kitchen uh, well some mornin like I want some grits and egg, I may cook some of those.
Int: May cook a little something?

Par: I'm havin' some oatmeal.

Int: Uh-huh.

Par: So if I don't have oatmeal I havin' some Kellogg Corn Flakes.

Int: (Laughs)

Par: (Laughs) and I drink a cup of coffee.

Int: Okay.

Int: Watch the TV, I hear ya. Well what about in the afternoons like um, like you, you do all your cooking, your breakfast your lunch and your dinner?

Par: Okay most of, most of the, I got Healthy Choice

Int: Uh-huh.

Par: Uh, the dinners, TV dinners.

Int: Okay, right.

Par: And I would eat them 3 times a day.

Int: Um-hmm.

Par: Not 3 times, sorry, 2 times a day.

Int: Right, twice.

Par: Lunch and supper.

The final extract contained in this section offers a clear example of how many men who return home after having a stroke event switch from being the primary person active in outdoor activities to the primary household member active in the mundane tasks of everyday life at home. Case 27, a widowed 51 year-old non-Hispanic white with a college education and annual income below $15,000, is now living with his girlfriend.
As he describes the household duties, case 27 notes that he has assumed the primary domestic responsibilities, declaring himself now to be “Mr. Housewife.” While he states that he doesn’t mind cooking, case 27 does have other feelings regarding different aspects to household maintenance such as washing and drying clothes. Other extracts presented in this section have illustrated noted differences between general statements about cooking and more specific statements about the ability to prepare certain types of meals.

The extract from case 27’s narrative presents a distinction between statements concerning household chores as a general abstract activity and a more specific statement that distinguishes household activities that the survivor doesn’t mind doing from those he finds practically bothersome. Up to this point, the few who did make such distinctions often expressed their continued reliance on their caregiver to continue or to assume the role of main domestic chef, with other chores left unmentioned or the participant doing the best he could in those areas for himself. Case 27 on the other hand, makes clear distinctions regarding his preferences in household activities stating that he doesn’t mind cooking. He’s always been pretty good at that. It is such things as ironing and folding clothes that case 27 finds to be problematic, and that his girlfriend Martha routinely “gets on him” to perform.

**Int:** Do you think there's a positive side of the recovery process?

**Par:** Well I think there is recovery. I recovered since I left the hospital from when I went in. I was pretty much (sighs) probably useless umm not totally but you know what I mean.

**Int:** Right.

**Par:** I could probably get up and still cook and all that stuff and take my baths but uhh…

**Int:** So now that you've had the stroke what does your future look like for you?
Par: Well I got a new occupation. I'm mister housewife now (chuckles). Bus driver. I don't have any problems. Actually, like I told ya, I've always cooked. I cook good Martha? Okay, so I don't have a problem with that. I hate laundry. You know she's working hard for me to do laundry, but I'm writing it off cause I just hate folding. I don't mind getting it, throwing it in and putting it in the dryer, but if you don't fold it you know, it wrinkles up and then you got to iron and all that.

Case 27 informs the interviewer that immediately after his stroke he was “probably useless.” He then says that he wasn’t totally useless, “but you know what I mean.” Case 27 then clarifies his embodied state right after the stroke indicating that he probably could still get up, cook and bathe for himself but not much else. In other words, he may score relatively well on the FIM, but be of little practical use in other activities that those around him had previously expected him to perform. Now, through the first few weeks of stroke recovery case 27 is experiencing a new self as “Mr. Housewife.” Through performing household chores and driving the kids to school, such responsibilities help his girlfriend and children, thus helping case 27 reconstruct his self as a useful entity. His functional recovery, in essence, has helped him to recover a sense of self that he finds to be of use to not only him, but to the others who are routinely around him. The activity still being negotiated seems to center around his girlfriend, the primary wage earner, wanting case 27 to assume a greater role in household activities, such as doing the laundry. Rather than state that he is physically unable to perform the activity, case 27 describes the activity as a nuisance and a problem in and of itself, for anyone, not just for who he is as a person recovering from stroke.

Many high functioning stroke survivors express eating and cooking as important aspects to everyday life. The way these stroke survivors reflect upon eating and cooking, however, is often at considerable odds to the way clinical measures like the FIM and FAI
deal with such practical concerns. While the functional ability to eat as it relates to handling a fork, chewing and swallowing, is not problematic to these survivors, many of them are intimately concerned with other aspects related to eating such as their diet and appetite. To suggest that diet and appetite are not relative to self-care is seemingly a narrow understanding of embodiment. Also, while cooking is seen as an activity that helps indicate one who actively participates in domestic chores, whether or not one prepares meals at home may depend on the type of meal preparation being done as well as the current living arrangement the stroke survivor finds himself situated in. That is, other factors that have no direct relation to stroke survival may have an impact on one’s experience of meal preparation. For instance, case 25 expresses that he was very active in domestic chores prior to having a stroke. Now he is minimally active. This can be seen as one lifestyle change directly resulting from his physical impairment after the stroke event. However, in describing meal preparation case 25 discusses how his mother insists on being the person who performs the activity, reprimanding her son when he attempts to prepare his own breakfast. His mother’s insistence on making all the meals for him drives case 25 “nuts.” This type of interpersonal dynamic between survivor and caregiver is not captured in the FAI.

For some, the inability to cook is a practical concern; for others it is not. This distinction is closely related to the household dynamic prior to having the stroke, as well as the types of activities the survivor himself relates to self independence. In the first two sections of functioning at home discussed to this point, two mundane activities, eating and meal preparation, are often reflected upon in complex ways. For some moderate and high functioning stroke survivors, having others cook for them is simply a part of life,
while for others it drives them “nuts.” Treating these activities as having universal meaning in and of themselves is not justifiable, at least in terms of how these practices are reflected upon by moderately high functioning stroke survivors who have returned home. Many survivors who would apparently be grouped as similar recovering bodies in a clinical sense express real practical differences in the significance mundane routine activities like eating, walking, and cooking have on their lived sense of embodiment.

**Watching Television**

With eating, walking, and cooking already outlined, the other activities these stroke survivors discuss are watching television, yard work, going fishing, playing bingo, driving, and swimming. While clinical experts may see television watching as an inactive orientation to the stroke recovery process, some stroke survivors may use television as their main link to the outside world, where social others (television actors or broadcasters) produce discourse that the stroke survivor actively participates in. Listening to, seeing, and thinking about language and interpersonal movement are social actions. According to Norman Denzin (2002 p.833): “we inhabit a secondhand world, one already mediated by cinema, television, and other apparatuses of the postmodern society.” In raising the issue of boredom as an aesthetic response and a phenomenological problem, Fredric Jameson (1991) looked at commercial television through an analysis of experimental video. He notes that boredom may be seen as a response to blocked energy (unleashed desires) rather than as a primarily objective property of things and activities. In a situation of paralysis, boredom may be a reaction to, rather than a result of, one’s lived environment. With boredom being a reaction and response to blocked energies, boredom itself becomes active. In this sense, watching television can be a productive activity.
Boredom, of course gains meaning from context, and what may be described as boring can be quite interesting. What Jameson finds to be the most interesting feature of the productive nature of television is its production of the simulacrum of fictive time. Television is an experience between people and machine. Within this mediation, the machine itself emerges as a material producer of human life and time. Jameson (p.76) explained:

Material or machine time punctuates the flow of commercial television by way of the cycles of hour and half-hour programming, shadowed as by a ghostly afterimage by the shorter rhythms of the commercials themselves… The simulacrum of the fictive seizes on such material punctuation much as a dream seizes on external bodily stimuli, to draw them back into itself and to convert them into the appearance of beginnings and endings…

In speaking of the simulacrum of the fictive Jameson is describing a world that exists only in the present moment. Nothing new is produced, but rather images are exhumed, exhibited, and displayed (Baudrillard 1983). That is, reality is circulated and manipulated through the mastering and controlling of imagery. Jean Baudrillard describes reality and meaning as an infinite web of simulacra, claiming that the first great formula of the new age is the merging of medium and message. Reality becomes a simulation that as Baudrillard (p.146) explained at the limit of reproduction “the real is not only what can be reproduced, but that which is already reproduced. The hyperreal.” The hyperreal is not only the limit of reproduction, and thus the limit of the real, but is also the limit of art. Television offers a medium of exchange between art and the real, which reproduces what has already been reproduced. The television world is then no different from the real, thus television time, or fictive time as Jameson more generally refers to it, is no different from real time.
In the examples that follow, activity level is measured by FAI scores one-month after stroke (see Table 4-13 of this dissertation). Case 9 (minimally active in leisure/work activities; moderately active in outdoor activities) offers an example of how time may become measured in accordance to the machine. For this stroke survivor, the rhythm of his day is mapped out in accordance to TV time, with parts segmented in half-hours and hours. The participant’s day is Louie Anderson, The Price Is Right, an hour of random voyeurism, Gunsmoke, and then the A-team. Being told that he cannot walk long distances at a time without risking another major health event, the participant has now become an active member of the videotextual world of television. Jameson (p. 78) noted that “video viewing indeed involves immersion in the total flow of the thing itself, preferably a kind of random succession of three or four hours of tapes at regular intervals.” While only expressing one random interval, noon to one pm, case 9 describes his immersion into the total flow of the hypervisual world of television imagery. This world minimizes case 9’s sense of bodily risk, therefore creating a realm of safety and reliability. Louie Anderson is always there at 10am. At least until his show gets cancelled, replaced with other talking heads.

Int: Does that go into the afternoon? What, I mean, in the morning after you get up, if it's humid, so you stay in when it's humid?

Par: Well, I would anyway.

Int: You would stay in anyway? (laughs)

Par: Yeah because Louie Anderson comes on. Got two parts to that. So that's an hour.

Int: In the morning?
Par: Yeah. It comes on at ten o'clock. And then we watch the Price is Right. And then I'll check outside to see how hot it is.

Int: After the Price is Right?
Par: Yeah, and there ain't a damn program on that I like from twelve to one.

Int: So then, what do you usually do between twelve and one?

Par: Watch television.

Int: You watch television anyway? (laughs) Between twelve and one?

Par: Yeah. It's like Dr. Zahn don't want me to walk on it. I asked him one day could I walk that mile. He said, "No".

Int: No? Why did he say that? He just-

Par: They'll find me in a heart attack or stroke or seizure. So, I don't walk. And then, you just look at somewhere or do something. And then Gunsmoke, A-Team.

Int: Is that later in the afternoon that you watch that?

Par: One o'clock it starts.

Int: Oh, one o'clock. What about, do you usually eat breakfast while you're watching TV and lunch, or do you take a break from TV while you're [eating]? No?

Par: I don't take no breaks from TV. It's not worth me goin' out and tryin' to do something.

Case 17 (very active in leisure/work activities; moderately active in outdoor activities) offers another glimpse into how the real and art are reproduced through television medium. The stroke survivor details his morning as waking up, turning on the TV, looking at Judge Mathis, then “crazy” Springer, and then Jenny Jones. Once this cycle has been accomplished, case 17 watches Springer, then Judge Mathis. After these 5 hours, case 17 gets up for lunch. After lunch, case 17 will watch some more television, informing “I have TV programs that I watch.” He then may switch media, recording and listening to music. He then may cook something before his wife comes home from work.

Int: After you get up in the morning, what do you do?
Par: Well, I'm usually up about 8 o'clock. I reach over and get my TV and turn it on. I look at Judge Mathis and crazy Springer, then Jenny Jones, or whatever her name is, Jenny James, and then I look at Springer again and then Judge Mathis again. Then I get up and, it's usually just looking at TV for most of the day. Go and get the lunch, or either go on and walk into the store.

Int: Then how about in the afternoon, what happens in the afternoon?

Par: In the afternoon I have TV programs that I watch and then I make some recordings on my tape, my recorder. I listen to music. I'll get up and cook something, or go in a fix my fishing lines and things like that.

In the evenings, case 17’s wife is home. She watches the news on television. During this time, case 17 goes into another room because he has no interest in observing news programming. After the news, case 17 returns and he and his wife converse, usually about the wife’s workday. As the participant states, he is not always “in the mood” to hear about his wife’s workday, but he “listens anyway.” As the extract shows, day and night is a process of listening and observing; either with reproduced images and sounds, or with his spouse.

Int: What about in the evening? What happens in the evening?

Par: Well, in the evening she comes home and then I'm sittin' in there looking at TV and she wants to turn on the news so she turns on the news. I go in the other room because I don't want to look at the news. And then we converse. We talk. She likes to talk about things that happened to her at work, and sometimes I'm not in the mood to listen to it but I listen anyway.

When asked about the help that his wife provides for him, case 17 says that she doesn’t help him. When his wife does household chores such as the laundry, she does it because it needs to be done. While she’s busy washing clothes, the stroke survivor is “busy looking at TV.” As illustrated, the sights and sounds displayed in television media often permeate the everyday lives of those included in the present sample.

… Well, there's nothing that she does for me that I need help with. Everything she does, she does because it needs to be done. But,
the clothing left to be washed, she'll wash the clothing and everything. While she's busy doing that, I'm busy looking at TV.

In discussing the worst part of his day, case 5 (moderately active in leisure/work activities; very active in outdoor activities) explains that it is from noon to 3 o’clock because there is no television programming that he really enjoys. Rather than participating in the TV world, case 5 just “sits.”

Par: About twelve to three. There's nothing on TV so I just sit.

Int: Oh, okay. So you mean from twelve noon to about three in the afternoon?

Par: Yes.

Int: There's not really much to do? Nothing on TV? Okay. So that’s why it's worse for you? Just because there's not much going on?

Par: Yes.

Television is often described as not only part of one’s daily experience, but also as a regular, routine time schedule that helps in keeping the world predictable and cogent. When television fails the stroke survivor, that is when the television schedule does not offer any programming that is satisfying for the voyeur, a “lull” in the day results, with the stroke survivor often finding himself alone and “just sitting.” For others, such lulls offer a good time for meal preparation and eating. In detailing his daily routine, case 10 (moderately active in leisure/work activities; minimally active in outdoor activities) further conveys the safety and reliability of television. After taking an early afternoon nap, the participant wakes up, “listens” to his television and drinks a glass of tea.

Par: After lunch, usually I take a nap [for] about an hour.

Int: What do you usually do after?

Par: Listen to TV and drink a glass of tea.
Case 1 (minimally active in leisure/work activities; moderately active in outdoor activities) offers another small extract that describes his daily world as participation in the TV world; an interaction where the television does the talking and the participant is quiet, taking his medicine.

Int: And what about later, so that's the morning and the afternoon, what about later in the day, what do you usually do then?

Par: Sit down and watch TV and be quiet and take my medicine.

Case 13 (moderately active in both leisure/work and outdoor activities) talks about how he is glad other household members are gone when he gets up. He watches television until noon and then gets bored. Before the stroke this is the time he would leave the house and go to some public setting. Now case 13 watches television, even though the programming that is offered to him does not meet his usual viewing expectations. Interestingly, from the extracts provided noon to late afternoon is often expressed as “time” that television does not offer much entertainment, forcing the stroke survivors to look elsewhere for sensory stimulation.

Int: What usually happens after you get up?

Par: What usually happens? (Laughs) I just look around. I'm glad everybody's gone.

Int: So you're usually here by yourself?

Par: Yeah. I watch television. I love to read. So I'm here by myself. Once it's 12 I say, "Uh-uh", bored. I'm used to bein' out that door.

Int: So like around 12 o'clock you start getting bored?

Par: I'm ready to leave, right.

Int: (Laughs) Okay. And so how is that? I guess coping with that now, knowing that?

Par: I just try to, most of the time I try to watch television or try to do somethin' that make the time pass.
Case 13’s sense of self is linked with his friendships rooted in a specific public setting, a club, where the people there are referred to as the “stump boys.” As the participant relates, he’d usually have one or two beers with the boys, cook some dinner for himself, and then watch television or a taped movie. As case 13 informs in the next extract, “my house is full of movies.”

Par: . . . . So I always go there 'cause I'm part of the club, what they call one of the stump boys. I love that and I stay there until about 6 and then come home. I drink me about 1 or 2 beers, I cook for myself, I love to watch television. I like to make uh, watch videos, movies. So I watch 'em and I make a lot of 'em. I make, I'll go to the video place and rent a lot of 'em and then make copies of 'em. So my house is full of video movies. I got about 100 and some movies. Right there, I crazy about movies. Scary movies and everything. So then I just love it. That's different.

Case 28 (moderately active in leisure/work activities; very active in outdoor activities) describes his day as “flopping on the couch” and watching a bit of TV. If he hears a noise outside of the home he may open his door and “peep out,” then return to his television watching. The stroke survivor’s friend, Jim, may stop by in mid afternoon to visit and chat. With television and Jim, case 28 is able to go through the day until it is time for dinner.

Par: And I come back and I flop down on my couch and put the TV on.

Int: Um-hmm. Watch a little TV?

Par: Watch a little TV. Then I hear some noise outside, I peep out, open the door or, and I come back in and watch the TV. [eats tv dinners]. . . .But I could sit here and watch the TV or Jim will come over and I look at the clock up there and it could be 2 and the next thing I know it's almost 5, you know?

Int: (Laughs)

Par: I say dog time for me to eat, you know?
While some stroke survivors express dissatisfaction with television programming around noon, for case 16 (very active in leisure/work activities; moderately active in outdoor activities), this is his favorite time to watch TV. Describing his self as a “TV buff,” case 16 has extensive cable broadcasting that offers 200 different channels. This expansive choice of programming may be one reason why case 16’s scheduling preferences differ from others presented to this point. Another reason, as illustrated in the extract, may also be a difference in the type of programming he finds enjoyable.

Par: Then, I'll get up, maybe look at the newspaper, or turn on TV. And I don't care certain every story but, that's about basically in the morning part.

Int: Okay. How about as the day goes on?

Par: Oh, me? I'm a TV buff. We have cable TV with all the channels. You know, 200 channels.

Int: Wow!

Par: So there's always in something to be, to see on TV.

Int: What's the best part of the day?

Par: Noon.

Int: Noon? Why noon?

Par: More things to, more activities, is um, or we'll turn on TV.

Int: So it's more of watching the television?

Par: Yes.

When asked what was the best part of the day before the stroke, case 16 describes after dinner when he and other family members would debate what to watch on television. This interaction is expressed by case 16 in the following extract as an intimate
family moment experienced in all households, as he states to the interviewer “you know it. You have family. You know.”

Int: What was the best part of your day then? [before the stroke event]

Par: The afternoon, at, when all together, after dinner, you know, then we'd all sit down and watch, well, in my house, my daughter, granddaughter, she had TV in her room. I had TV in the bed, in the room, got the big TV and we'd all get together, you know? And debate about what we're gonna see. You know how it. You have family. You know (laughs).

Int: Yes (laughs)

Par: I'm not gonna say "Well, then go to your room and watch your TV" (laughs).

Case 2 (minimally active in both leisure/work and outdoor activities) describes his day as staying in and watching television. In the next extract, when asked what the best part of his day is now, case 2 answers that it is evening time because that is when news and other television programming he enjoys comes on.

Int: Yes, so you spend all of your day at home?

Par: In the house. Right here is where I was.

Int: And you watch television?

Par: The only thing, to watch television.

Int: Television. You like watching television?

Par: I like it.

Int: Yes. What do you like to watch the most?

Par: Well I like everything. The programs. The news.

Int: And what is the . . . moment or time of day or part of day that you like the most?

Par: The evening because I watch television and all the news.
Several of the participants discuss getting their news from the television. For example, case 3 states in the below extract that he gets his news from television, at least in part, because newspapers are not delivered to his area.

Par: Get the mornin' news.

Int: On the television? Newspaper?

Par: Yeah, television. We live too far out to have a newspaper. We, (laughs) at noon. Then we'd have to go way down the road down there to get it. So, I usually listen to news there.

Case 14 also discusses using the television in order to get the “news of the day”:

Par: I rest and then I get up and I usually go and then I chat sit down and chat or watch the TV and watch the news and see what the news of the day

Int: And then what time is supper?

Par: Supper we eat it from five o'clock till six o'clock and then after six we'll usually go back to do usually I usually sit around and talk with the fellows and watch TV and watch the news programs and so on

Case 23 (moderately active in both leisure/work and outdoor activities) will wake up and watch the news, and then prepare a meal, look at the newspaper, filling out the crossword puzzle:

Int: When you first get up in the morning what do you normally do?

Par: Usually the TV is on and if there's anything interesting I'll watch the news. If not, then I'll get up and maybe fix something to eat. Just uh read the newspaper, crossword puzzle first.

Case 23 also discusses how his television viewing has changed. Due to a loss of hearing, the participant must use his remote more often than he used to. Particularly, when two images are in dialogue on the television screen, case 23 must adjust the volume to hear what is being discussed. Thus, one physiological change case 23 is experiencing is illustrated in the below extract in which he discusses his television activity.
Par: You know a lot of people, we get like that. We don't know what somebody is saying to us and instead of asking them because I figure if you say something to me it's better for me to ask you rather than somebody else.

Int: Right.

Par: The minute somebody's giving an interview on TV and stuff like that say oh wouldn't you think he might? That's when I reach for the remote.

Int: (chuckles)

Par: You see before the remote goes for only changing channels. Change the channel and you set the remote down.

Int: That's right.

Par: Now you gotta have it by your side all the time.

Int: (chuckles)

Case 17 (very active in leisure/work activities; moderately active in outdoor activities) discusses the changes in life he is experiencing in terms of never being at home before. As head Deacon, the participant was frequently at his church and “constantly on the go.” Now, at home much more than he is used to being, case 17 wants to purchase a computer, but his wife seems to be hesitant due to financial considerations. The following extract shows the stroke survivor’s desire for greater interpersonal communicative possibilities in the home. Computers, therefore, are not just for kids. Adults who find themselves spending more time at home due to specific reasons may also desire having a variety of communicative, media outlets.

Par: Oh, yes. My activity level has changed. Because I'm used to, because I'm, this time last year, I would never be home. I would be at the church or something, because I was the head Deacon of the church, and consequently that kept me on the go constantly. And I want to buy myself, get myself a computer so that will keep me a little busy. Run my electric bill up a little bit (laughs). Which my wife is totally against, but nevertheless, she will, she'll give in pretty soon. That's the only reason I haven't purchased it because she said "no".
While case 17 continues to negotiate with his wife about purchasing a computer to help keep the stroke survivor busy during the day, some of the participants have already entered the digital age, communicating with social others via electronic mail and the Internet. The extract presented below from case 18’s (minimally active in both leisure/work and outdoor activities) narrative provides an example. Whereas television offers an opportunity for watching, the computer is described differently as “Internetting” and “learning.”

Par:  I have my computer.

Int:  You work on the computer?

Par:  Reading.

Int:  Reading?

Par:  Internetting. Learning

Case 19 (minimally active in leisure/work activities; moderately active in outdoor activities) also details the hours he spends on his computer “lookin’ up stuff” and sending electronic mail. This computer activity is what case 19 normally does during the day, but there are days he has energy and stamina to work in his garage or on one of his automobiles. This extract shows that while many of the stroke survivors orient their day around television programming, some have entered the world of the internet, where time is not as structured. Rather than presenting specific times, internet time is described as “hours.”

Int:  What type of things do you do during the day to kind of pass the time?

Par:  Sometime I'm not the computer. If I get on it I'm usually on it for hours lookin' up stuff, sendin' e-mails. And that's about it. Every once and a while I might feel energetic enough to go outside and do something out there but, even if I feel energetic about it I got to make my mind up to do it and stick to it.
Int: What type of things do you do outside?

Par: Usually cleanin' somethin' in the garage or rearranging the garage or workin' on one of the cars.

For case 25 (minimally active in both leisure/work and outdoor activities), computer activities are not seen to offer much personal satisfaction. The participant describes how his day is tightly regimented to a schedule of medication and mealtime. In the below extract the stroke survivor details his activities throughout the day as “just watching TV.”

Int: But umm so tell me about your typical day like when you wake up in the morning?

Par: Uhh I just watch TV

Int: You just watch TV

Par: Yeah umm take my medicine you know everything is regimental I mean she's already, I mean she's got the hours down

Int: Really

Par: Yeah, but especially that 9:30. I can't take them at 9:00. And lunch is by 12:30.

Int: Wow it's right on the clock!

Par: Yeah and 4:30-

Int: And 4:30 is dinner?

However, when discussing employment possibilities, case 25 says that he “wasn’t called” for computer work. He informs the interviewer that he “can’t stand the computer. Oh, I hate it.” He wonders, “what the hell do they see in that crap?” Although his daily routine seems to consist of sitting down, watching television, taking medication, and eating food, he tells the interviewer, “oh God, I can’t sit still.” He states that he has to use his hands or his head, but is not sure what will be available for him.
Par: I mean I wasn't called for it. I don't know what I'm gonna do next. I can't stand the computer oh I hate it what the hell do they see in that crap.

Int: Sitting still?

Par: Oh God I can't sit still. I got to use my hands or my head or I gotta do something. So I don't know what's gonna be available for me.

Int: You'll find something

Par: Yeah.

Case 21 (moderately active in leisure/work activities; minimally active in outdoor activities) notes that his day consists of taking his diabetes medicine, eating breakfast, then turning on the television and watching. While watching television, case 21 also organizes his day. Although not working outside, he does handle bills, making certain utility companies do not make an error:

Par: I take my Diabetes medications, later I have breakfast and during that time I turn on the TV to watch the news to see what is happening. And from there I sit to watch a little television, organize my day and the things I need to do. Because, although I do not work outside, I have to check the telephone bill because sometimes they put phone calls that you did not make and to later work.

Case 21 also discusses how he uses his hands while watching television. Using a metal pole, the stroke survivor moves his arms, hands and torso while watching television. Thus, for case 21, television time is also exercise time. This extract illustrates material activity that a few stroke survivors may do during what is generally perceived to be an inactive practice.

Par: Well the first thing you tell them is that you understand what they are going through that to keep a positive mind that he do some exercises to maintain strength in his muscles that he find an area. For example, you see this chair here? This is for when I sit and watch television. I have a metal pole and since the chair allows me to freely move my arms, while I am seated I am moving my arms. I have a broomstick which I put here with my two hands and I move my torso. So, while I watch television I am also doing exercise. . . .But this is the area that I have so that I do not get bored and put the chair here and the chair allows me enough movement
for both arms and the legs so I don't bump into anything. It proves to be a means of personal exercise.

While case 21 exercises during TV time, case 26 (minimally active in both leisure/work and outdoor activities) discusses watching television and passing out as the routine activities that make up his day. He sees his future as dying, with his only hope for the future being that he keeps breathing. This extract offers a poignant example of how the future is understood differently by people who are often grouped as similar bodies by clinical measures like the FIM and FAI.

Par: (laughter) That's easy. I wake up and turn on the TV. ‘Cause I like sports and maybe the TV. We used to have cable. We don't have the cable anymore. But this table, this TV in the bedroom works better than the one outside.

Int: What do you do after lunch?

Par: We go watch TV. Wind couple clock and we go back to bed.

Int: Okay, what does your future look like?

Par: (he and his wife chuckling) I hope I have a future. Just watch TV and then pass out.

Int: Okay. (chuckles)

Par: Maybe I hope I just sit down have a stroke. I'm gonna die. (chuckles) That's the future.

Int: What do you think life will be like a year from now? You'll be watching TV and passing out?

Par: Just keep breathing (everyone laughs).

Although similar to case 26, among others, in terms of television watching as the primary activity he does throughout the day, case 31 (very active in leisure/work activities; moderately active in outdoor activities) states that after dinner he and his son will go out of the house to some public setting. One such outdoor activity that he does is
go fishing. This extract shows that even people who may generally orient everyday life around eating and watching television, this does not preclude them from also performing more active tasks during the week, particularly if the stroke survivor has family members willing and able to do things with him.

Int: What do you do?
Par: Well, now, here, I wake up, and I go watch television.

Int: Okay, and then, you watch TV, and sit here, until when?
Par: I'll stay here all day.

Int: All day? Then lunchtime comes around and…
Par: Lunch, then dinner, and every now and then we go out somewhere.

Int: Oh, you all go out?
Par: I go out fishing and things like that.

The last three extracts that have been presented offer the various levels of activity that these stroke survivors participate in throughout the day. That is, most will simply sit or lay down and observe their television screen until it is time to eat, or another person enters the area. Case 25 does physical exercise while watching television. Case 31, like a few others, will break-up television time with outside time. That is, after watching some television and eating a meal the stroke survivor will go out with family members, performing an outside activity. Such outside activities make up the last section of the current outline of everyday lived experiences of stroke survivors who have returned home.

**Outside Activities**

In Chapter 7, while discussing the importance of locomotive activity in everyday life, many of the stroke survivors provided accounts of what it is like when they go
shopping. One of the major shifts expressed in the shopping experience is that the stroke survivors have difficulty walking through store aisles, with many afraid of falling or bumping into social others. In the second section of the current chapter regarding television the stroke survivors provided accounts not only of watching television, but also on their daily activities, which mainly consisted of television and eating. One other activity around the home that is discussed in some detail by sample participants is that of lawn care and outside gardening. For instance, case 8 (moderately active in outdoor activities; stating he does all necessary outside gardening work) discusses waking up and performing yard work, stating, “now, this morning I got up and I trimmed the hays, hedges around the house.” Case 12 (very active in outdoor activities; stating he does regular weeding and pruning activities), also briefly mentions his yard work activity, stating,

“I use the mower,” when asked about the type of physical activity he performs. Case 21 (minimally active in outdoor activities; stating he never does outside gardening activity) describes gardening activity that for some reason is not indicated by his FAI score on that activity, telling the interviewer “I check the plants. The ones you already said were pretty. I like them, but recently I have not been able to make them work right. And like that, my life has become very simple.”

In the following extract case 1 (moderately active in outdoor activities; regular weeding and pruning performance) states that he does not “deal with the kitchen,” because all that he does is outdoor work. One major theme found in the stroke survivor narratives is a former self expressed as meaningful through outdoor activity, and a current self that is attempting to get back to doing the outside things it has always done. Yard
work is one such activity many stroke survivors find they can no longer perform to the same extent they had prior to having a stroke. Further illustrated by the next abstract is case 1’s understanding that activities like yard work will help him by using, but not overdoing things. Interestingly, helping his self is linked to bodily activity.

Int: What kind of things do you help out with?

Par: Help out? Oh, no, I don't deal with the kitchen ‘cause I do outside work. Well, I don't rush out there. Whatever you feel a little bit doin'. I picks up the leaves there a little bit and set around and I'm very weak. I do as less as possible, but I'm not in the house sittin' down. I stir because I figure that would help me, my body, by using it but not too much. I'm jack of all trades and master of none. Anywhere on the outside. If it's a will it's a way if I have to get somebody to do it. And I say, for instance, I let my yard and things go off because I ain't able to do it. Well I got my grandchild to plant those peas. I've had the seed back there for a month or so, but I couldn't do it. So you just have to ease up and let go.

Like case 1, in the next extract case 30 (very active in outdoor activities; performs no weeding or pruning) talks about going outside and doing a little bit, but not wanting to “overdo it.” In presenting these extracts regarding yard work, not only do they illustrate a difference between who and what many of the participants were before the stroke compared with who and what they are now, but they also illustrate the types of outdoor home activities stroke survivors attempt and how they determine physical limitations.

No, I try to uh, I've been workin' a little bit tryin' to clean up here and move the, we're movin' the porch around to the back there. And I want to sod this over here, but I'm not, I don't want to overdo it. I'll just do what I can do 'til I get tired and then I come back in.

Similar to cases 1 and 30, case 4 (very active in outdoor activities; egular weeding and pruning performance) does some yard work but finds himself limited to what he can do since having the stroke. As the next extract shows, having a younger family member around to perform such chores as lawn care, not only helps in maintaining home
appearance, but may also serve as a way the stroke survivor can go out and perform an activity with interpersonal supervision and familial companionship.

Int: You mowed today?
Par: Yeah.

Int: Wow! The yard is beautiful, do you do all the gardening and stuff?
Par: Oh, ah, ah…

Sister: He did, but now he's limited.
Par: My son is home and he, ah, so, some, yeah.

Int: So you worked in the yard a lot?
Par: Yes, uh-huh.

Case 9 (moderately active in outdoor activities; no gardening, but heavy household maintenance) also discusses doing a bit of yard work after his spouse “started pickin’ about it yesterday.” In the following extract the stroke survivor describes how he went outside and put some branches into piles, but is not certain how much he can do without “overdoing it.” Not sure if doing outdoor activities such as this will cause physical harm, the stroke survivor primarily stays indoors watching television.

Par: I don't take no breaks from TV. It's not worth me goin' out and tryin' to do something.

Int: Yeah.

Par: I'd give help picking up yard waste, branches, putting them in piles in the yard here. Wife started pickin' about it yesterday. I was lucky to get out there and, an put 'em on pile, one of the piles out there. But I don't know if I'm, I'm be dead or what's gonna happen.

In the following extract, case 11 (minimally active in outdoor activities; currently never does any gardening or household maintenance activities) is described as an
“outside person.” The stroke survivor’s wife discusses how he was hardly inside the home before he “got sick”, and misses yard work a great deal.

Int: So, that's the best part of your day, is when you get to go outside?

Par: Yeah.

Wife: Because he is an outside person. I mean before he got sick he pretty much stayed outside. You couldn't hardly keep him in the house. I mean, and I know he misses that a lot because, like yard work and stuff like that, he can't do anymore.

Case 2 (minimally active in outdoor activities; occasionally performs light gardening tasks, no home maintenance activities) tells the interviewer that before having the stroke he would go around the neighborhood and mow lawns for money. This provided a little bit of revenue, but also served as a means of social interaction between his neighbors and himself. Now, unable to mow lawns, the stroke survivor is also unable to communicate with his neighbors like he had only a month ago.

Par: Well, before the stroke I would cut lawn. Yes, I would landscape because my pension is very small. I receive very little money.

Int: And did you cut the lawn for money?

Par: Of course, when they paid me.

Int: Before the stroke, in this year?

Par: Yes this year, this year lastly a few months ago. I cut lawn, watered the lawn. I would go out around here to the neighbors and neighborhood I would cut lawn, they could talk to me and that's how I spent my day.

Another outside person, case 3 (minimally active in outdoor activities; regular weeding and pruning, no household maintenance activities), tells the interviewer how he took a farm over in his youth, working hard his entire life. Now he can’t even use any of his three lawn mowers. In the following extract not being able to work the way he would
like to is expressed by the stroke survivor as a major difference before and after having a stroke.

Par: I took over a farm when I was 12 years old, with a couple of old mules, 40 acres, worked hard all my life then come up here and can't do a damn thing. Don't need to do nothin', really. You know, I got enough money to last me the rest of my life. If I could just get out and enjoy it now. (both laugh). 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 bush hog, haven't even put the bush hog on the tractor. Give you an idea how I can't do it, but I’m plannin' on it.

Int: Any other differences from before your stroke to now in terms of what you did in the mornings?

Par: Just can't work like I'd like to. (sniffs).

In the next extract case 29 (very active in outdoor activities; regular weeding and pruning, and repairs small household items) offers more details into how he determines physical limits. That is, the stroke survivor presents a description of what he does to ensure that he does not “overdo” things. Like the other extracts provided regarding yard work, case 29 “like’s pushing the lawn mower.” Not mowing since his stroke he plans on purchasing a self-propelled mower that will enable him to get outside and do some of the yard work he had done prior to having the stroke.

This extract presents a good example of how the stroke survivors who describe themselves, or are described by others, as an outside person currently handle physical limitations when attempting outdoor work. These extracts, coupled with the information provided by their FAI score, also illustrate how the ways in which these stroke survivors answer their activity level depends on how they orient their physical performance in terms of their typical day. That is, some may focus on the activity they did up until their stroke a month ago, believing that they will be back out doing what they’ve always done
in a short time. Others may find their lifestyle completely altered by the stroke, answering the FAI questions in terms of their current physically limited self.

Assuming that all the participants adhere to measurement instructions the same way is an assumption not rooted in material evidence. The variation found between FAI score and personal narratives is indicative of how people reflect on life through an intertwining of past, present and future experiences. This, however, can become highly problematic in scaled measurement that demands people reflect on their behavior in a very specific time frame, and may have little relevance to their lived understandings of who and what they are.

Par: Now I used to work on the yard and work really hard 3 or 4 hours. It didn't matter. Now I can't do it. I am limited to do that. Yes, like if I go out there to work on the yard I have to come inside in a shorter time than before. At some time I used to work out there four hours straight. Now I probably can work half an hour and I have to go inside to cool off a little bit and drink some water. And like pushing the lawn mower. I haven't done it yet because of the limp in my leg. It might be a little difficult, but I don't think I'm limited to do it. I think I can do it. I am gonna get me a lawn mower where its self propelled I have a push mower and I'm gonna get a self-propelled mower. That way it will be a lot easier for me to help me with the pushing.

While many stroke survivors describe their days as staying at home and taking things easy, there are occasions where some of the stroke survivors attempt different types of social activities. For instance, case 11 (minimally active in leisure/work and outdoor activities) and his wife discuss his recent experiences at bingo. The wife discusses how case 11 used to always be “go, go, go.” He did the outside work and she the inside work. Now, case 11 cannot do as much as he used to do in terms of outside activities. Bingo is the example the participant provides of an activity that is difficult to keep up with.
Par: Yeah. That's what I mean. Like I said, I'm not against women's lib or whatever, but I think, here at the house, or (laughs) or, maybe we'd go to Bingo together or somethin' like that, you know.

Wife: That's my pastime, is bingo.

Int: Do you go to Bingo now?

Par: Well, every once in a while I do, but, here, lately I've just, I'm slowed down and I can't keep up. I mean I don't play but one sheet at a time. I can't keep up.

Int: It's hard to keep up with the Bingo?

Par: Yes, it's hard to keep up with it. And I'm like I don't know, like we have a speed game sometimes, and I can't keep up with the numbers. I (snorts), so…

Int: Did you make a decision, "well, then I'm not going to go anymore?" Or are you going to keep trying?

Par: Well, I tried, but not as often.

Wife: Every once in awhile he'll go play bingo.

Par: I'll, maybe Saturday or Sunday, like that, just to get out of the house. To break the monotony around the house.

Case 11 also discusses his experiences when he goes out to eat, stating that he is more reluctant to go out to eat since the stroke. However, he does not think much when out shopping, for, as the participant states, he gets into his motorized cart and goes. This extract illustrates the point that different public settings are interpreted and acted upon in different ways by the stroke survivor. In the bingo setting, case 11 has a difficult keeping up with the pace of the activity. At a restaurant, case 11 is embarrassed by the fact that food will hang from his face, with others seeing him. He is also fearful of falling down in the bathroom. When out shopping, however, the stroke survivor feels relatively at ease, at least as long as his wife is by his side. Thus, not only are there differences among stroke survivors in the ways they maneuver within and relate to public settings, but there
are differences experienced by the same stroke survivor depending on what social context and public environment he finds himself interacting with. For example, while case 11 begins with stating that he feels “a little uneasy” at restaurants, he does not give a place like Wal Mart any thought.

Par: Well, a little uneasy. But I know that, I mean, they, they're, I think they're lookin' at me but they may not be. And, uh, then when they, I mean, some people they are lookin' at me and sayin' well, you know, look at what a sloppy eater he is, you know? And, it's disgustin' and somethin' like that, you know? Um, so, I eliminate that.

Int: You eliminate it by not going out as much?

Par: Right.

Int: So you, you're reluctant to go out because of how others might see you?

Par: Yes. Now as far as shoppin'? In the grocery store or Wal-Mart or somethin' like that? I mean, I go and with her and, and I get in my motorized vehicle and go all around and don't think nothin' about it.

Case 11 also discusses how others in public settings may offer assistance with such tasks as going to the bathroom and getting money out of his wallet to help pay for merchandise. Since the stroke, someone is constantly with case 11, be it his wife or a helpful other.

Par: Well, you know, I'm afraid of that I might fall, but I know that people look after you. So, I mean, if a woman is a cashier, she'll make arrangements for a man to go to the bathroom and do whatever she can.

Wife: Sometimes I do let him go in the store and I sit in the car. Just to let him know that he can do this by his self.

Int: Does that help?

Par: Yeah. Just like I go in the store and I, like up there in the express lane they got three 4-packs of Pepsi for eight dollars. And if I'm havin' problems getting money out, if I ain't it in my pocket and got it in my wallet, they, the lady will-

Wife: She's so nice. She's a real sweetheart.
Par: The lady will help me get it out.

Wife: Since he's had this stroke he never goes anyplace without me.

Par: Well, I know that but-

Wife: I'm constantly with him.

A few of the stroke survivors reflect on the public interpersonal assistance they receive. For instance, case 16 (very active in leisure/work activities; moderately active in outdoor activities) discusses the “encouragement” he receives from friends when out playing cards. This following extract provides an interesting example of how friends can provide social support for the stroke survivor, cheering, or rooting, the person on when attempting a physical task.

Int: What do you find most helpful that other people do for you?

Par: Encouragement.

Int: Encouragement?

Par: Yeah. Especially my buddies, you know. You know, you can do it "oh, man come on, you're just sittin' here bein' lazy", knowing they're trying to help me.

Int: How does that make you feel?

Par: It makes you mad and make you get out and do it.

Int: (laughs)

Par: (laughs)

Int: So it is encouraging?

Par: Yes, you're right. And we've been buddies for 40 years and 30-year friendship, you know it's "oh, man", when we're playing cards, you know, and I might drop a card and I might "hey, man, get me the card". "Man, you can pick up the card". (laughs) Somethin' like that.
Case 20 (very active in leisure/work activities; minimally active in outdoor activities) discusses the people who look out for him, making certain things are taken care of for the participant. These people are his wife “of course,” and his golfing buddies. This extract provides another example of the type of social support familiar others provide stroke survivors.

Int: Do you think that the way others feel about you has changed since your stroke?

Par: Uh, with my golf buddies. I think they look out for me more. And my wife of course. She looks out for me, my wife now.

Int: How do they look out for you more?

Par: Well just to make sure that things are taken care of for me.

In case 28’s (moderately active in leisure/work activities; very active in outdoor activities) narrative, the participant reflects upon his passion for Karaoke, measuring his personal wellness by his ability to get back “into life.” That is by going back out to local clubs and singing with friends and social others. In the following extract, the importance of outdoor activities that is failed to be captured by the FAI, in that the measurement scale offers no specific information on what activity helps the stroke survivor find meaning in his everyday lived experience, is expressed by the stroke survivor himself as he reflects on his personal experience.

Par: I feel like I’m getting back up.

Int: Right.

Par: Into life, you know? So, so I went to the Stardust club where I used to sing and they were all glad to see me and wanted me to sing. So I sang one song. And everybody clap say same old Iceman.

Int: They was glad to see you there?
Yeah. I started back there so that make me feel good, you know? And then you know, the guy bring me back, dropped me off and walked me to the door and make sure I get in, you know?

But I tell him, "Okay, man, I call you a couple days. Named Willie. But he like to sing, too."

The Iceman is a singer, and as the participant informs the interviewer, singers stick together. His friend Willie will drop him off at home on the nights they Karaoke. The next extract shows that this social interaction is not only important in defining who and what case 28 is, but also in making daily life more meaningful.

All the singers stuck together, you know, singin'. So we go around them different clubs, you know? We got some like bapity clubs that know our name around here and we always go and sing.

Hey, I'm talkin' to a celebrity here. (laughs)

And I felt good. Like on my birthday last Thurs, what the 6th of September? Day before last.

Oop. Happy belated birthday Mr. Jones.

Thank you. And Willie come by and pick me up. We went out to eat. Matter of fact we went to his girlfriend house. She cooked for us.

Oh, that was nice.

So Willie said, "I'm bringin' a surprise out there". I think you know him, but they call him Iceman Jones.

Ahh! (laughs)

And she said, "Oh, that's Iceman? The one that sings?" He said yeah. So I went out there you know so we all got together that night, that Thursday, and we went to Stardust Club. Which is in Beach City at the Jackson Hotel. So that's why I used to sing there a lot. And Hollywood Night and Howard Johnson, the Beer
Belly, Charlie’s Place, you know, I would sing all these places. I'm known in all the places.

The Iceman not only interacts with intimate friends, but also meets new people when he sings. For instance, as the participant continues his description of when he and his friends went out for his birthday, Iceman describes an encounter he had with a new acquaintance:

Par: And we went there and we sung that night. Matter of fact I, I'm glad I went 'cause I met a girl that work up there. She named Sally. She married and she has a husband there. And she's a singer. And so she's heard me sing, she say, "You name Iceman. You work for the school security." She said, "I work there, too". I said I never seen you before.

Int: She knew who you was?

Par: So I said, "Yeah". And she said, "My name is Sally". I said I'm Iceman. She said, "Oh, glad to meet you Iceman". She said, "Oh, you sing nice". I said, "You do, too. You sang, I heard you sing Aretha if that's Aretha Franklin up there". But she say, "Well, we better sing a duet together, learn to get a duo, you know?"

Int: Right. And do a song together.

Par: So the other guy, Willie, and all of 'em, you know, yeah, yeah, yeah, y'all should sing a duet. So I say the next time I come down here so, because I'm not on my own. She said, "Yeah, I see you with your walkin' cane", and all this here. She said, "Willie brought ya?" Yeah, he brought that. I said next time we'll sing one. She said, "Okay, nice to see you. I'll tell 'em at the office that I saw you, I've met Iceman".

Being able to go out with friends and sing at local clubs enables case 28 to express who and what he is. This form of expression, as detailed in the extract provided, has helped the stroke survivor “get back into life.” While still not back at job as a security officer, the Iceman is back doing what he does best: singing. Not having friends or family members around who are interested in the same type of outdoor activities may severely limit the types of things one does after returning home after stroke. For instance, while case 11 discusses going to bingo and out to shops and restaurants, one
activity he used to do “everyday” was go fishing. As he explains to the interviewer, he would go fishing again if he had someone willing to go with him:

Par: No. I ain't given up.

Wife: There for a while, he did. He did. That's all he wanted to do was lay in the bed. (laughs) And I guess between me and Miranda, you know, we come in and, starting to do things and…

Par: Well, me and Miranda, ah-

Wife: Well, that's his buddy"

Par: (laughs) My fishin' buddy. When we lived in Panama City I used to go fishin' every day (snorts). I'd let out 8:30 9 o'clock and, and we'd stay out there until 3 or 4, and just fish. Nobody but just me and her, and, I don't know. We came back up here and…

Int: So you used to fish everyday but now you don't? You don't go anymore?

Par: Well, I'm waitin' for, I mean, I wait for the nurses but, and, my kids, they go with me, but they're workin' and they don't have time. And-

Wife: And he definitely can't go by himself. And I hate fishing.

Int: So if someone would go with you, you might go?

Par: Yeah.

Not able to go fishing right now, however, gives case 11 a personal goal to achieve. Therefore, seeing that in the future he will be back fishing enables the stroke survivor to reflect upon his current experiences not as problematic, but rather as presenting him with a personal challenge.

Int: How about, not, you know, fishing as much as you used to and things like that? Do you find that frustrating or not?

Par: Well, no I don't. ‘Cause I know that eventually I'll get back to it, and everything. So I don't give it much thought as a problem.
Case 17 discusses a similar experience, but does not seem quite as sure things will return to normal as is case 11. The following extract illustrates how the stroke survivor is currently dealing with what he plans to do and his uncertainty of what his body will enable him to do. With his fishing poles visible in the hallway, the stroke survivor intends on going fishing. If the activity does not work out right, then he will know that fishing is not an activity he can perform, and his plans will alter accordingly. Similar to some of the outdoor people who define their physical limits by attempting certain outdoor yard activities, case 17 plans on testing his limits by attempting a favorite hobby of his; fishing. Stating on the FAI that he actively pursues a hobby 3-12 times in 3 months does not provide information on how a specific outdoor activity figures into the meaning-making process of living at home after having a stroke. The extract below does provide this type of insight.

Par: So there are many things that I want to do and planning on doing. I'm planning on going fishing. In fact I've got my fishing poles standing up in the hallway now. I plan on going fishing pretty soon and if that doesn't come out right I won't go fishing no more. I'll just make plans on giving my fishing poles away.

For case 24 (while categorized on the FAI as very active in outdoor activities, states on FAI that he never actively pursues a hobby), his plans for the future focus on the outdoor activity of boating. The stroke survivor discusses how he not only misses the activity of boating but also how he misses the interpersonal relations he has with customers who pay to ride on his boat when he and his wife take seashell collecting trips. As this extract illustrates, outdoor activities gain meaning not only through functional performance, but also from social relationships that develop within such public settings.

Par: You know the customers and talking with them and I really miss that but I can still do stuff that I like to do. I'm still capable, and I believe I am, of taking my boat out. I haven't taken out since the stroke but I've been up on it. I've checked
it out and got the engine working and everything. So I know and I can probably, next month sometime, take it over to Marco Island for a couple of months. I take the shell club out and my wife and I collect seashells. And we usually take the boat over there a couple of months and I take also some people out who pay for the expense of being there and we go shelling on the north shore mud tracks.

Swimming and golf differ a bit from the outdoor activities that have been presented to this point in that they require more complicated physical movements than do fishing, singing, and bingo. In other words, swimming and golf require more functional capability than walking. They are activities that require specific synchronous movements with arms, wrists, legs, and torso. Fishing also requires such a synchronous movement when casting, but the body is stationary, with the movement required in casting being bending of the elbow, shoulder flexibility and a snapping of the wrist. If one’s “casting side” is unaffected from the stroke, then such movement presents little difficulty. It one’s “casting side” is impacted, then the stroke survivor, such as case 17, must go out and try to see what he can do. Golfing and swimming, however, require bilateral limb movements, thus if either side has been affected after stroke, such activities become problematic.

A few examples are provided below from stroke survivors who loved to swim or golf, and would like to return to their recreational passion. For example, in the next extract case 6 (minimally active in leisure/work activities; very active in outdoor activities; states on FAI he never pursues a hobby) discusses his desire to get back into the ocean and swim like he used to do, stating that the local pool does not offer enough space or enough freedom of swimming style. The participant reflects on how he used to swim in the ocean, describing a time when he had a swimming race with the lifeguard. This biographical information is provided by the stroke survivor in describing who and
what he was and who and what he plans to be. The swimming pool does not offer the
stroke survivor the physical challenge that he is looking for.

Int: You said you're planning to do exercises or something, are there any things like
that you think?

Par: Yeah, I think that if I could get back in the ocean and start swimming.
‘Cause I love to swim and I love the ocean, but I don't like pools.
Not these foot-wadin' pools they got today. We got one right down here, what is
it? A fifty-footer, isn't it?

Norma: Where is that?

Par: The pool, down the street.

Norma: Is it a fifty?

Par: I think it's a fifty, twenty by fifty or somethin' like that. And, hell, I dive in there
and I'm, take one stroke and I'm at the other end. And I was used to, in Miami, I'd
go swimmin' every morning in open water and I'd swim about four or five miles
every morning, see? And I used to race the lifeguard and she couldn't
understand how I could swim so fast.

Int: So you'd beat the lifeguard at swimming?

Par: Yeah.

Int: So that's something you'd like to do again?

Par: Well, I'd like to have that opportunity to be back on the beach. I mean right on
the water, and just go swimmin' in open water where you can swim laterally, you
know along the shoreline, not just straight out.

Case 9 (minimally active in leisure/work activities; moderately active in outdoor
activities; states he never pursues a hobby on the FAI) also reflects on the pleasure he had
in swimming in the sea. The stroke survivor informs the participant that such a swim
would “cool me down.” Saying that he is grateful for the life he has had, case 9 wonders
why he is not able to do what he would like to do, suggesting that the cause may be
metaphysical. This next extract is similar to the reflection offered by case 6, with a
discussion of the benefits of the ocean on one’s sense of embodiment. Thus, while the 
FAI informs the researcher that the stroke survivor is not actively pursuing a hobby, it 
fails to capture what the participant would like to do in the near future (what he plans to do). Such future plans may have more importance for the stroke survivor than his present 
activity, especially at one-month after the stroke event.

Par: But no. This is like, stuff like that, I want to go. You see, I know, if I get in the 
water, it will cool me down. So, like I said, we were, I was born and raised in 
Miami and Key Largo, and I can dive in that water and get cool. (snaps fingers) 
You don't think it take me a second. Once I'm totally wet I'm comin' out. There 
ain't no shark getting' me.

Int: (laughs)

Par: But, no, I'm grateful enough to have the life I've had. And there's a reason for it, 
yeah. God's stoppin' me or somethin'.

While some of the stroke survivors like cases 6 and 9 discuss their desire to return 
to the ocean, other stroke survivors, such as cases 14 (moderately active in leisure/work 
activities; minimally active in outdoor activities; pursues hobby at least weekly) and 27 
(minimally active in both leisure/work and outdoor activities; states he never pursues a 
hobby), discuss a desire to return to the golf course. For example, case 14 describes how 
not being able to do what he would like, go golfing, can become frustrating. Similar to 

Par: I wouldn't, yeah I would say sometimes it’s frustrating that you can't do if you want 
to do something. I used to play golf. Now I can't do it. I got a brand new set of 
clubs (laughs). I can't use them now. They're sitting there and, but anyway I said 
one day I was gonna go back and try it anyway. But I think now that, I think it 
pretty soon it's a good time to see if somebody else can't use em (laughs). It's 
frustrating, but you sit and you enjoy life. If you don't enjoy life, forget about it.
The last example provided in this chapter comes from Bo Gator’s (case 13; moderately active in both leisure/work and outdoor activities; pursues a hobby at least weekly) narrative. The stroke survivor not only expresses a desire to return to normal, but also a desire to learn how to perform new activities. In the extract presented below Bo Gator tells the interviewer that a year from now he will be riding a motorcycle like social others he has seen, referred to as the Joy Riders. Someone will have to teach him how to ride a motorcycle, but as Bo Gator states, “I believe I can do it.” These stroke survivors orient their selves to the outside world in different ways. Some believe they will return to their favorite outdoor activities. Others are concerned that they may never be able to fish, swim, or play golf again. And there are people like Bo Gator who want to enjoy life to its fullest, learning new activities and participating in new social settings. This extract shows that future plans can offer interesting examples of who and what stroke survivors plan to become.

Int: What do you think life will be like for you a year from now?

Par: I'll be ridin' a motorcycle. I say ‘cause I always wanted a motorcycle. ‘Cause them guys out there, they race motorcycles and they got a big motorcycle club called the Joy Riders. So I always wanted one and I say I'm gonna get one. But somebody gonna have to teach me how to ride, and I believe I can do it.

At this point in the dissertation, a variety of self-care and social activities have been presented from the 31 stroke survivor narratives. The ways in which these stroke survivors attach meaning to particular events or personal practices have been analyzed. In chapters 5 through 8, data was presented in a manner that is designed to follow the suggestions of Margaret Lock (1993 p.148) who concluded that “pressures by others to produce tidy answers and ‘Just So’ stories should be resisted by researchers, suggesting instead that we take an eclectic approach, content with a body that refuses to hold still.”
In taking this advice I have attempted to describe and report on stroke survival from the respondent’s approach. That is, I have tried to follow the advice of Aaron Cicourel and study social action through studying the world of stroke survival as a world made meaningful through emerging, stabilized, altered, and destroyed belief systems.

My presentation of the participant extracts and the comments made regarding these extracts is an attempt to present an analysis that is as close to the everyday understandings of the people I have studied as scientifically possible. Narrative extracts have been presented as a representation of the meaning structures that are reflected upon and used by the stroke survivors during their qualitative interview. These reflections are anchored in the interview situation, a situation that frames their self as a stroke survivor, but many of these reflections are also examples of the tacit knowledge they use in orienting their selves to their everyday worlds. That is, I have used participant extracts as representations of the underlying structure to the world of stroke recovery. Chapters 5 through 8 have been designed to specifically describe and outline the logic-in-use of the participants, attempting to explain the real world of stroke recovery by examining the routine practical activities in the everyday lives of the people I am studying.

In discussing the interaction among self, body and world, I have presented a group of participants whose embodiment has shifted (e.g., dys-appearance), and in turn so has their worlds to varying degrees for varying reasons. In assessing functional ability, this dissertation has presented embodied agents that refuse to hold still when they are experienced in the interactive, relational, and social worlds of everyday life.
This dissertation has presented data generated from a sample of veteran, male stroke survivors who were discharged to the community. In this report I have presented functional ability assessments as well as an assessment of activity level using clinical measurement scales. What has been indicated is that this sample of stroke survivors consists of moderate to highly independent people. Those stroke survivors who do require some assistance in activities of daily living tend to need minimal physical help in grooming, bathing, dressing, and transference. As indicated in Chapter 7, many of the participants use assistive devices while walking. The FAI analysis indicates that level of outside activity as well as domestic chore responsibility and active pursuit of a hobby differ among these participants. The ways in which these participants differ in such activities was addressed in Chapter 8. Overall, Chapter 4 provides a quick, general glimpse of functional and activity level for this sample. Chapters 5, 6, 7, and 8 provide insight into how this sample actively produces meaningful realities in daily life after a stroke event. Such insight is not garnered from the other-centered gaze constructed in measuring these object-bodies, but rather these insights are generated from an intense focus upon the subject-body through analyzing participants’ narrative constructs of the self, body and world they live by.
Comparing FIM and FAI Results with Stroke Survivor Narratives

With some of the major themes presented in this dissertation discussed in the previous section, the final step is to compare the general sample information provided by FIM and FAI data in Chapter 4 with the general sample information provided by the sample participants themselves in chapters 5 through 8. The first thing I will do is discuss the demographic information provided in Table 4-1 of this dissertation and explain how age, race, marital status, and income may factor into lived experience. Next, the FIM information provided in Tables 4-2 through 4-8 will be reviewed, linking this information to relevant information presented in the qualitative data. The final part of the current section will be a discussion of routine activities and lifestyle, linking the FAI data provided in Tables 4-9 through 4-13 with participant narratives.

With the stroke survivors included in this sample ranging in age from 40 to 84 years old, the ways in which the participants relate their functional abilities with their age differs accordingly. Namely, for someone like case 25, age 40, who is wheelchair bound after the stroke event, he wonders why and how such a drastic health situation has occurred. For those in their 70’s and 80’s, there is more variation in how age is linked with their current health condition. For example, case 6, age 84, does not feel any different than he had prior to his stroke diagnosis, and believes he has been misdiagnosed. Case 2, age 78, finds his deteriorating health as impacting his feelings of happiness and usefulness in terms of his marital and social relations. Case 8, says that age is “10%” of the reason for his current functional status, with the stroke itself impacting functional ability 90%. Case 7, aged 70, states that he is fortunate. Medical experts performed surgery on his carotid artery prior to having a “full-blown stroke.”
The lack of stamina he experiences when outdoors is primarily related in his personal account to age and another health condition, particularly to his mechanical heart valve.

When asked how age relates to their current functional capabilities the stroke survivors often compare themselves to others around them who are in the same age category. Particularly in terms of stamina and loss of short term memory, such interpersonal age comparisons are deemed as a natural component to the aging process. Age, therefore, is used differently by the stroke survivors as a means of assessing functional capability, with some finding shifts in activity performance as a natural part of having lived a long life, and others believing the if the stroke had not occurred they would be much different physiologically. Which way age is interpreted often depends on the level of functional impact the stroke has had on the participant’s everyday routine activities.

While employment status was not included as a personal factor in this dissertation, the impact the stroke has had on those who were not retired at the time of the health event was indeed one of the major themes reflected upon by the participants. Obviously age has an impact on employment status, with those in their 70’s and 80’s no longer employed full-time outside of the home. For those stroke survivors in their 40s, 50s, and even 60s, having such a health event not only interrupts their daily lives in terms of dressing, bathing, walking, and eating, but also in terms of their ability to provide financial support in maintaining their current living situation. Thus, whether or not one was employed at the time of the stroke will have a major influence on how the stroke is expressed in terms of impacting lived experience.
While participant’s race was categorized as African American, Puerto Rican Hispanic, and non-Hispanic white, it is difficult to determine any general differences among these groups from the data provided. There is some evidence within the current sample to suggest that African-American stroke survivors prefer taking things easy than do the non-Hispanic white participants, but this issue would require a much more in-depth study of the issue with more participants in different regions of the country. The impact of cultural-historical factors may differ in the southern region participants were drawn from for this dissertation than in other areas found in the United States.

Out of all the personal factors included in Table 4-1 of this dissertation, marital status appears to have the most salient impact on the stroke recovery experience. One stroke survivor notes this as he informs that when nobody else is around a person has little choice but to function independently. The majority of participants were married and living with their spouse. This factor may greatly impact the reflections presented in chapters 5 through 8 where many of the narrative extracts present a lived experience where the stroke survivor’s wife and children aid in locomotive stability in public, home maintenance, meal preparation, and shopping activities. Those living alone who rely upon neighbors or friends for personal assistance seem to experience these forms of help differently than those who are aided by their wife.

Receiving personal care from a neighbor of friend may be seen as troublesome, while receiving help from a family member is most often reflected on as a positive interaction where love is mutually expressed. Some of the participants’ wives, however, work during the day, with the husband at home expected to take care of general household chores. Such home dynamics factor into how a stroke survivor assesses his
current functional ability after stroke. That is, some may be able to take it easy, relaxing with their spouse eating, watching television, and going shopping throughout the day. Others may feel more pressure to cook, clean, and do certain things independently, thus “pushing it,” so that when their spouse returns home from a day of paid labor she can relax rather than taking care of her husband and performing additional physical activities in the home.

Looking at the FIM results provided in Tables 4-2 through 4-8 in Chapter 4, 18 of the 31 participants indicated slight (increase in FIM rating of 3) to more substantial (increase in FIM rating of 37) improvement in functioning from the time of discharge to the one-month interview. Ten of the 31 participants indicated slight (a decrease in FIM rating of 1) to more substantial (decrease in FIM rating of 45) functional needs at one-month in comparison to their needs at the time of hospital discharge. The FIM was conducted through participant communication of the type and amount of assistance he requires for each given activity included on the measurement. While still in the hospital, it could be that the stroke survivor had limited understanding of his functional capabilities due to the constant medical assistance provided in the hospital as well as the different environmental situations he would encounter in his own home as well as out in the community.

Also, level of functioning often increases dramatically only a few days after the stroke event. Furthermore, as indicated in the review of literature provided in Chapter 1, those who are indicated on the FIM to have at least volitional movement after the stroke are the stroke survivors most likely to experience increased motor-functional improvement. With the stroke survivors included in this sample at least moderately
independent in the majority of self-care tasks, functional improvement over the first 1-3 months would be expected. In general, this is the experience participants relate to the interviewer, stating that they are getting better, with many anticipating getting back to normal. Those who do not express improvement often discuss a lack of energy and dramatic locomotive changes (for instance going from walking to being wheelchair bound) as the issues most prevalent in their recovery experience. Also, those who were engaged in paid employment prior to the stroke often express concern over what they will be able to do in terms of paid labor in the future. Comorbidities such as diabetes and chronic back pain will also impact how one reflects upon their everyday functional ability.

In breaking down the FIM scores, noting the tasks in which at least 19% of the sample indicate needing at least minimal assistance, grooming, bathing, dressing, bed and chair transfer, and walking up and down stairs are indicated as the FIM tasks this sample needs the most assistance in. The fact that these tasks are generally the activities reflected upon the most by the stroke survivors themselves during the qualitative interview adds validity not only to the FIM scores but also to the assumption that the qualitative interviews are accurately reflecting the participant’s everyday functional activities. Stairs, not generally discussed in the qualitative interviews can be explained by the fact that those who have difficulty walking up a flight of stairs most often do not attempt stair mobility. Interestingly, data seems to indicate that the vast majority of participants live in a single-story dwelling, further decreasing the need to negotiate stairwells. As indicated in Chapter 6, bathroom and dressing work as well as transference are important factors in participant accounts of important changes to everyday life.
Also interesting is that eating, found to be a task most of the stroke survivors manage to negotiate themselves is extremely important in everyday life, requiring much personal effort, if eating is understood differently than as the task is defined by the FIM. Most of the stroke survivors can use a utensil, chew, and swallow. On the other hand, as reflected in Chapter 5, most participants also must constantly monitor their diet, and evaluate shifts in appetite. While this is difficult to measure in a few seconds, looking at one’s range of motion, these aspects are important in stroke recovery. With appetite and dietary regimen important factors in maintaining and/or improving one’s current health state, then it may be that such issues should be included when measuring functional ability. Furthermore, while able to use utensils and swallow, a few of the stroke survivors may not notice if food is dangling from the mouth from time to time. Capturing such aspects is a fairly hit or miss activity when rating a person at a specific moment in time, depending on whether or not the person hits or misses himself. However, in personal narratives issues of public embarrassment when such eating mistakes occur, this functional change can have a major impact on the frequency one eats around social others besides one’s spouse.

Other than diet and appetite, stroke survivors also reflect medication maintenance as an extremely important daily activity. Stroke survivors may require someone reminding them of when to take their medication. Others experience physiological effects they relate to a certain pharmaceutical, making personal decisions regarding when as well as the amount of the chemical to ingest. Such decisions obviously have significant influence not only on everyday life, but also in assessing drug effectiveness on a population that lives in the community. Whether added to a measurement instrument
such as the FIM or included in a different instrument, issues of diet, appetite, and medication intake should be evaluated when assessing functional changes before and after stroke.

As illustrated in the scatterplot presented in Figure 4-1 of this dissertation (p. 80) the interaction effect between FIM and FAI score has a strong positive linear relationship. This relationship seems to exist until overall FIM rating ranges from 120 to 130. This may be indicative of a ceiling effect of the FIM where functional changes in those stroke survivors rated as highly independent in self care tasks are not captured. Such an effect is one reason why the current sample offers important insight into the FIM and FAI measures. More specifically, with extensive qualitative interviews conducted with highly independent stroke survivors living in the community, personal narratives may provide insight into functional changes among them that are not captured by the FIM. In breaking down the FAI into the three factors of domestic chores, leisure/work, and outdoor activities, insight into functional differences come into clearer focus.

For instance, 20 of the 31 participants are scored as minimally active in domestic chores. Some express that they are no longer able to “play with the stove.” Safety comes into this assessment in that one may spill hot food or liquid, or one may forget to turn off the stove increasing the possibility of a fire. Others express the desire to do such things as washing dishes or doing laundry but do not currently have the stamina to do so. Thus, for some of the stroke survivors who are minimally active in domestic chores it is because they are unable to perform such activities. These differences in domestic chore ability are not captured by FIM score, but can be captured by the FAI, illustrated the need for both measures in assessing functional changes before and after a stroke event.
However, as expressed in the personal narratives, the ability or inability to perform domestic chores may not be able to be captured due to the fact that some stroke survivors did not perform these activities before the stroke and have not attempted to do so since their stroke. This variance may be one reason why the FAI uses the construct of lifestyle rather than functional ability. Thus the FIM measures changes in functional ability while the FAI measures changes in lifestyle. But as the analysis of interaction effects indicates, it is difficult to separate one from the other.

Issues of walking and driving a car are often expressed as important considerations in the lives of stroke survivors. Measuring walking outside in terms of number of times per month does not capture the type of walking (e.g. walking in the mall or to the grocery store as a method of physical therapy, or walking around the yard to get some “early morning air.”) or the importance shifts in balance or type of assistive device used during mobility has in changing one’s lifestyle. Such meaningful experiences to the activities measured by the FIM and FAI are illustrated in the participant narratives. Thus, while the data used in this dissertation indicate that the FIM is useful in measuring raw functioning, and the FAI is useful in providing a rough account of activity level, they fail at capturing how certain aspects to physical functioning and routine activities are experienced and “dealt with” in various ways by those being measured. While this information may not be of much importance in understanding the body as object, it is extremely important in understanding the body people live by, that is, the body-as-subject, or being in the world. Knowing that high functioning stroke survivors’ level of outdoor activities decrease still fails to capture the variation in terms of the importance such activity shifts have in their everyday lives. Some find computer and television
entertaining enough that decrease outdoor activities are of little practical concern. For others, their sense of self is defined as an outside self, and therefore changes in outdoor activities are of much everyday practical concern.

Some stroke survivors anticipate returning to their normal routines, while others are beginning to make adaptations to a new lifestyle. In concluding the current section, it is suggested that the framework provided in Figure 4-2 of this dissertation is used in assessing the meaning of stroke recovery. Level of functional independence can be incorporated using FIM rating, with activity level implemented through the FAI in a general sense. However, the meaning of functional ability and level of participation in routine activities requires an analysis of how those recovering from stroke interpret and reflect upon such clinical constructs. It is my belief that incorporating all these forms of stroke assessment provides a more accurate account of the self stroke survivors live by, thus maximizing the congruence between scientific typifications (abstract meaning) and the actual (practical, lived) meaning of the concrete actors (highly independent stroke survivors) being studied.

**Conclusion**

At the beginning of the dissertation I mentioned that, following Cicourel (1964), the underlying theme of this report of medical knowledge and functional assessment in the everyday lives of stroke survivors was to construct a theory of instrumentation and a theory of data that attempted to disentangle the observer’s presence and procedures from material labeled as data by the observer. Through analyzing data obtained from scaled measurement instruments as well as from personal narratives, I have attempted to assess functional ability after stroke from multiple perspectives. At this point in the dissertation I have outlined the ability of scaled measurements such as the FIM and FAI in assessing
everyday functional activity, suggesting that meaningful activity must take into account the reflections and narrative constructions of functional activity as expressed by those being studied. Considering the amount and complexity of the narrative extracts included, one who has read up to this point may feel inundated by participant accounts. I have attempted to present the meaning of functional activity one-month after having had a stroke as the participants themselves accounted for such activity, comparing these accounts with the data provided by clinical measures. Obviously, however, my presence as an observer helped to construct the narrative accounts in my decisions of what extracts to include and how to include them. While ultimately the quality of the presentation is made meaningful by the response of the reader, after reviewing the final product, I am satisfied that a general understanding of how these 31 participants have experienced everyday life after their stroke event has been adequately presented.

At the beginning of Chapter 3 the primary research questions were listed as follows: 1) What insight do measures such as the FIM and FAI provide researchers and medical practitioners regarding functional status of stroke survivors in home and public settings? 2) Are stroke survivors who are categorized in the same recovery category really having a similar recovery experience? And 3) do such measures (FIM, FAI) provide a valid account of the actual daily experiences of stroke survivors who are living within the community? In answering the first question outlined, it has been suggested that the FIM offers a reliable and fairly valid measure of raw motor functioning, while the FAI offers a general measurement of participation level in domestic chores and certain leisure/work and outdoor activities. However, this understanding, while helpful in highlighting some of the general functional and lifestyle themes that will reflected upon
by highly independent stroke survivors in their accounts of home and public life, often
fails to capture the differences in how these themes are made meaningful in and of
themselves as action-in-practice. This point leads into the second question regarding
whether or not those who are categorized as similar by such measurement scales reflect
similar recovery experiences when discussing everyday life during qualitative interviews.
Chapters 5 through 8 have offered some of the differences in lived experience from this
group of stroke survivors.

Those who rated lower on the FIM in certain motor tasks are the participants who
reflect on such tasks when offering their personal account of everyday life. What is
lacking, however, is the importance interpersonal relations, such as family support and
public interaction with social others, has on how functional shifts after a stroke are taken
into account. While this social interaction may not be of importance for the object-body,
as reflected in chapters 5 through 8, it is very importance for one’s sense of embodiment
in everyday life. This conclusion leads into the third question that asks about the validity
of measurement tools in providing an account of functional ability for stroke survivors
who are living in the community. That is, the construct that the FIM and FAI fail to
measure is that of embodiment, and socially, it is embodiment that links one’s self to the
everyday world.

To summarize, scaled instruments such as the FIM and FAI seem to provide a
relative accurate account of the body as an object that can be measured and probed, but
fail at providing an account of how this body helps in constructing the underlying
structure of the worlds people live in. Medical knowledge is often the logic-in-use in
descrribing the lived body, but social worlds also involve personal reflections of what
makes the term independence meaningful in everyday life. This point goes back to a statement made earlier in this dissertation in which I stated that people do not simply focus on biological aspects of the body, but also incorporate social realities into the meaning of stroke recovery. While the biological aspects are adequately accounted for in medical practice, social realities require more than observing. An understanding of social realities requires listening to and reflecting upon members’ accounts.

My suggestion is that when analyzing various treatment strategies or orientations to physical ability, one should study the interrelationships of everyday practical lived experience, the body, and one’s expressed sense of self, regarding who and what they are. In other words, when developing treatment strategies for human bodies, one should first address the going bodily concerns of those being treated. Holstein and Gubrium (2000) locate the active construction of self in particular self stories that are told and performed in particular scenes found in everyday life. If the clinical self told by medical professionals differs from the lived self as told by the stroke survivor who has returned home, then the practical relevance of medical stories outside of the clinic must be brought into question. As Holstein and Gubrium noted (2000 p.), “identity remains what local interpretive practice makes us out to be.” Thus, in order to provide the best, most accurate data of the lived body, the clinical understanding must be incorporated into the understandings brought forth in lived experience, much as it is for all of us in everyday life.

One failure of the current research is that it accounts for embodied experience after stroke for high functioning stroke survivors at one point in time (time of the qualitative interview). To provide a more accurate account of stroke recovery, such scaled
measurements and qualitative interviews should be conducted across time, at one month, six months, and twelve months, with data analyzed for not only individual changes across time, but also analyzed for shifts in changes in what is meaningfully reflected upon by stroke survivors and how they describe their lived experience through time.

**Implications**

Agreeing with Ellis-Hill et al. (2000) my study has concluded that the meaning of the body is socially defined. Ellis-Hill et al. recommended that health care practitioners incorporate narrative as well as physical skills into rehabilitation practice. Incorporating the life narrative approach into stroke rehabilitation enables practitioners to prepare treatment plans relative to the real world settings of patients. This approach also permits rehabilitation practitioners the opportunity to construct more personalized interventions for stroke survivors. My study has concentrated attention on moderately-to-high functioning stroke survivors who have received minimal, if any, professional rehabilitation services after their most recent stroke.

Motor-FIM score at time of admission is the strongest determinant of rehabilitation length of stay (Stineman et al. 1995). With resource allocation determined by treatment efficiency, and treatment efficiency measured by subtracting motor-FIM score at admission from motor-FIM score at discharge, the patients who are expected to gain the most motor-functioning after rehabilitation are the patients most likely to receive rehabilitation treatment. That is, large-scale treatment evaluation and service enhancements are determined by measurable changes in physical functioning as indicated by Functional Independence scores. In establishing an efficiency pattern analysis, Stineman et al. (1995) illustrated that for those rehabilitating after stroke, the highest functioning category at admission (FIM motor score ranging from 64 to 91) is the group
that nets the lowest functional gain. Duncan (1997) found that one must have at least volitional movement at baseline in order to achieve motor functional gain. Yet, those with a high degree of functional independence at baseline will likely produce less gain in motor functioning than those who are low-to-moderately independent in the self-care tasks measured on a scale such as the FIM. With this knowledge in hand, when deciding what patients should receive rehabilitation, those who are already high in motor functioning and do not have severe speech problems resulting from the stroke are most likely to be discharged home, with little if any follow-up rehabilitation services provided. This is because such determination in resource allocation is based in traditional therapy methods and traditional quantitative functional assessments. Rehabilitative specialists have not adequately addressed rehabilitation in home settings.

Previous research has noted a lack of close congruence between physical recovery and psychosocial recovery (Dowswell et al. 2000). Even stroke survivors who are categorized as high functioning, highly independent in self-care tasks often report low levels of social and leisure activity. This complexity is partly illustrated in Figure 4-1 of my study in which those with high FIM scores illustrate a wide range of scores on the social activity index (FAI). This lack of close congruence between physical recovery and psychosocial recovery is further illustrated throughout the qualitative analyses provided in Chapters 5-8 of my study. Time and again moderate-to-high functioning stroke survivors reflected on how their lives have changed since having the stroke. While a few of the participants in this study, such as cases 6 and 7, noted little change in their daily lives, the vast majority of participants recount how they have slowed down, how routine
tasks such as mowing the lawn and putting on their socks have become a chore, and how their social activities have become greatly limited.

Despite physical recovery, stroke survivors often continue to experience a decline in social activity (Dowswell et al. 1997). Even in terms of physical recovery, however, improvements generated in rehabilitative treatment for stroke survivors are not always sustained after discharge, resulting in poor long-term outcome for stroke patients. Looking at Table 4-3 of my study, very few of the participants had identical scores at both times of assessment. While 18 of the 31 participants indicated at least slight improvement in motor functioning from discharge to one month after discharge, 10 of the 31 participants indicated a decline in motor functioning during this time. Although motor improvement may not be likely for every stroke survivor, home rehabilitative services could help sustain the survivor’s current functional status. By providing rehabilitative services at the patient’s home, health care providers could support continued functional status for those moderate-to-high functioning stroke survivors who are currently experiencing a decline in motor functioning during their first month home. This service could help maintain patients at their home, preventing more costly full-time nursing care placements.

Dowswell et al. (1997) reported that home visits from a specialized nurse during the first year after stroke helps in stroke adjustment. With varied practical and emotional difficulties that arise after a stroke, this effect of adjustment did not produce significant improvement in quantitative outcome measures (Dowswell et al. 1997). What Dowswell et al. (1997) failed to analyze, however, is the importance of sustaining one’s current level of motor functioning in terms of adjusting to home life after stroke. While
quantitative outcome assessments may produce valid, reliable measures of physical functioning in self-care tasks, they are unable to assess the psychosocial complexities found in the everyday lives of stroke survivors. Relevant to my study, although visits from a specialized rehabilitative therapist would likely not result in significant quantitative motor-functional gain, they would be of value to many stroke survivors and their caregivers in terms of helping the stroke survivor sustain current motor functioning and improving the survivor’s quality of life in areas such as interpersonal concern, attention, and interest. In other words, many of the moderately-to-high functioning stroke survivors described in my study would benefit from rehabilitative services; particularly services that focus on psychosocial aspects of stroke survival.

Holmquist et. al. (2000 p. 178) stated:

One could always argue that the average burden of care per patient in hospital would increase and call for increased staffing if the less care-demanding patients were to receive rehabilitation in their own home to a greater extent. However, any expected savings would imply the bringing about of a total re-allocation towards less resource-demanding forms of rehabilitation.

Patients living at home are more likely to spend some time each day in self-directed physical exercise than those involved with in-patient rehabilitation. Patients and caregivers also reported less resource utilization and greater satisfaction with home rehabilitation compared to routine rehabilitation (Holmquist et al. 2000). In the Holmquist et al. study, one of the most satisfying aspects of home rehabilitation expressed by stroke survivors was the greater capacity of home rehabilitation programs to incorporate patient’s needs and desires into the treatment practice. My study has indicated that through the use of quantitative and qualitative data, needs assessment can encompass motor functioning capabilities and psychosocial aspects of human experience.
in the context of the patient’s home. From such assessment techniques more efficient home rehabilitative services can be designed for moderate and high functioning stroke survivors, resulting in optimal rehabilitative outcomes.

With stroke rehabilitation devalued in the world of biomedicine, optimal rehabilitation services are often precluded in the current health care system (Kaufman and Becker 1986). In traditional rehabilitation treatment the stroke survivor must conform to and be deemed suitable for a given therapeutic service. However, since stroke recovery is a term used in describing a series of complex, widely varying pathways, many stroke survivors find few opportunities to receive rehabilitation from their current health care provider. Stroke survivors are commonly consulted for physical, occupational, and speech therapy. Once the patient establishes the ability to meet the goals of these therapies, formal rehabilitation is commonly ended and the patient is discharged.

Primarily, the stroke survivors in my study established a relatively high functional motor score and did not require intensive speech therapy, quickly returning home after their stroke. What many of the participants expressed in the qualitative interviews, however, is that they now face new challenges that often intertwine both the physical and psychosocial aspects of who and what they are. Such challenges often fail to be addressed in traditional rehabilitation techniques because they require an in-depth understanding into the everyday lives of the stroke survivors and their caregivers.

For example, little attention has been given to helping patients effectively manage the psychosocial consequences of a dys-appearing body, that is, a body that now becomes of central concern in routine, mundane activities. As illustrated in my study, even high functioning stroke survivors find their bodies slowing down, not being able to do what
they could do only a short time before the stroke, and fatiguing much more rapidly than they used to. Patients and their caregivers could benefit from some education programs aimed at helping them understand the recovery process, including the physical, psychological, and social aspects. It is this type of understanding my study has attempted to present, not only as a means for stroke survivors to express their concerns but also as an illustration of how qualitative data may be used to alter rehabilitative strategies. Developing a rehabilitative program that conforms to patient needs rather than forcing the patient to conform to a universally structured rehabilitation program is needed. Those stroke survivors currently neglected by traditional rehabilitation programs, which focus only on the motor-functional aspects of recovery often ignoring the psychosocial components of a person’s everyday life, are of particular concern.
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BIOGRAPHICAL SKETCH

Craig Boylstein began his education at Indiana University of Pennsylvania, where he earned his Bachelor of Arts degree in psychology and Master of Arts degree in sociology. He began work towards his Ph.D. at the University of Florida in the Department of Sociology.

Upon completion of the dissertation, he expects to continue teaching and research in an academic setting. His areas of interest include social psychology, methodology, theory, medical sociology, and aging and disability studies. Specifically, he holds research interests in institutional ethnography, social interaction, chronic illness, and communicative systems.