

The experience of time in the transition from hospital to home following stroke

Maude Rittman, PhD, RN; Christopher Faircloth, PhD; Craig Boylstein, PhD; Jaber F. Gubrium, PhD; Christine Williams, DNSc; Marieke Van Puymbroek, MS; Charles Ellis, MA

Department of Veterans Affairs (VA) Rehabilitation Outcomes Research Center, Gainesville, FL; University of Florida Colleges of Nursing, Gainesville, FL; Department of Sociology, University of Missouri, Columbia, MO; Miami VA Medical Center Geriatric Research, Education and Clinical Center, Miami, FL; University of Miami School of Nursing, Miami, FL

Abstract—This paper reports findings related to the transition from hospital to home during the first month after discharge following acute stroke. Qualitative data were obtained from in-depth, semistructured interviews with 51 male stroke survivors and their caregivers. Data were analyzed with the N6 software application, designed to assist with qualitative data analysis. Stroke survivors described experiences related to changes in the temporal order of life, disruptions in sense of self, and strategies used to manage time. Findings indicate that changes in the temporal order of life are related to functional impairments and disruption in the taken-for-granted body. At 1 month post-discharge, survivors are struggling with establishing routines in their day and coping with an increased amount of idle time. In conclusion, strategies for managing increased idle time are “passing time,” “waiting on time,” and “killing time.”

Key words: cerebrovascular accidents, recovery of function, rehabilitation, self-care, self-concept, time management.

INTRODUCTION

Stroke is the leading cause of disability in the United States and the third leading cause of death [1]. Over 4 million people are living with the effects of stroke, and over 700,000 Americans suffer a stroke each year [2]. The incidence of stroke increases exponentially with age and is consistently higher for males than females, suggesting that the number of survivors with significant

residual physical, cognitive, and psychological disabilities will continue to increase as the population ages and more survivors live longer with the aftermath of stroke [3,4]. At least 80 percent of stroke survivors are discharged home to continue recovery, yet little is known about the transition experience of stroke patients after discharge home [4–6].

Sociologists and anthropologists have documented that the occurrence of a chronic illness such as stroke often leads to a loss of independence and biographical disruption, in which people experience chaos and discontinuity

Abbreviations: ADL = activity of daily living, FAI = Frenchay Activities Index, FIM = Functional Independence Index, GDS = Geriatric Dependence Scale, ICD = International Classification of Diseases, SD = standard deviation, TV = television, VA = Department of Veterans Affairs.

This material was based on work supported by the Department of Veterans Affairs, Health Services Research and Development, Nursing Research Initiative 98-183, awarded to Maude Rittman and the VA Rehabilitative Outcomes Research Center, Gainesville, FL.

Address all correspondence to Maude Rittman, PhD; Rehabilitation Outcomes Research Center (151-B), North Florida/South Georgia Veterans Health System, 1601 SW Archer Road, Gainesville, FL 32608-1197; 352-374-6108; fax: 352-271-4540; email: Maude.Rittman@med.va.gov.

in their lives and sense of self [7,8]. Adjustment to living with a chronic illness demands reordering temporal aspects of one's daily life and reintegrating one's sense of self. The experience of time is recognized as an important feature of transitions and the adjustment process [8]. Little is known about how stroke survivors manage changes in the experience of time during the transition from hospital to home, the impact of the experience of time on one's sense of self during the transition, or the strategies stroke survivors use to manage time during this transition period. This paper reports findings related to the transition from hospital to home during the first month after discharge following acute stroke.

Loss of independence is one of the most difficult transitions people experience in the United States [9], and most of the research on recovery poststroke is based on a biomedical model examining changes in functional variables such as walking, getting in and out of bed, transferring to a sitting position, and sphincter control. Functional abilities and limitations have an important role in the transition from hospital to home and significantly affect one's experience of time. Neurological and functional recovery is believed to occur most rapidly in the first 1 to 3 months after a stroke [10,11]. Within 1 week of acute stroke, 20 percent of survivors will walk normally, while another 20 percent of survivors continue to be unable to walk without help at 6 months [12]. In the Copenhagen Study, a community-based population study of 1,197 acute stroke patients, researchers report that the best neurological outcome is reached within 11 weeks from stroke onset and the best recovery of basic self-care and mobility skills occurs within 12.5 weeks in 95 percent of the study cohort [13,14]. In the transition from hospital to home, stroke survivors and their caregivers are faced with adapting to changes in functional ability and role performance. These changes are directly related to psychosocial transitions during the first month after discharge home.

Basic activities of daily living (ADLs) include not only mobility but also other self-care functions that a person must be able to perform to be independent. These functions include dressing, bathing, feeding, toileting, grooming, and transfers, e.g., bed to chair and in and out of the bath. Findings from population-based studies indicate that independence in self-care ADLs improves for 88 percent of patients within 3 weeks of stroke onset, and 24 to 53 percent of survivors improve 6 months to 5 years after their stroke [10]. This literature indicates that bodily

disruption poses a significant challenge to stroke survivors and that change continues to occur over time.

Transitions

A transition is a passage from one life phase, condition, or status to another and is embedded in the context of a particular social situation [15]. Parkes introduced psychosocial transitions as a conceptual framework for research into managing chronic illnesses. Psychosocial transitions occur when a major change requires an individual to restructure ways of looking at the world and to develop new ways of living in it [16]. Parkes studied changes across time among primary caregivers of stroke patients and reports depression as highest during the hospitalization period. Depression decreased 6 to 10 weeks after discharge home, but family dysfunction increased during this time period, reflecting the often chaotic experience of adapting to the transition [16]. The psychosocial transition framework focuses attention on the postacute phase of recovery and changes that occur across time.

A salient feature of a transition is that it is usually precipitated by a triggering event that initiates a change in the way individuals look at themselves and their situations [17]. Stroke is a triggering event with initial concerns on survival during the acute phase of treatment. Once survival is assured, the survivor is faced with managing the loss of independence that accompanies disruption in the functioning body, ushering in the onset of a transition [7]. Two salient features of the transition following stroke are that the process (1) occurs over time and (2) involves changes in identities, roles, and behaviors [18]. These changes influence the way survivors experience time.

Recovery across time following stroke involves transitions, an under-researched area of chronic illnesses [6,19–21]. Most of the research on transitions after stroke has used qualitative methods. Quantitative methods have not been used to study transitions, because they do not adequately capture the contextual features of the process. Findings from two qualitative studies indicate that the transition process is initially chaotic with changes in family relationships, caregivers taking one day at a time, and caregivers struggling to hang onto hope and coping with exhaustion [22,23]. The chaotic period is followed by a reorganization, during which life becomes more predictable and less stressful [23]. The experience of time is a significant aspect of the transition process. Bury argues that the unfolding character of chronic illness requires

understanding experiences within a temporal framework [7]. In suggesting that the onset of a chronic illness creates biographical disruption, Bury argues that only the passage of time and trial and error provide the mechanism for reestablishing some degree of certainty in the lives of those learning to manage symptoms associated with a chronic illness [24]. Little is known, however, about how stroke survivors manage the passage of time.

However, a growing body of literature on survivors' understanding of their disabilities reflects the complex process survivors experience while adapting to changes after stroke [9,25–35]. Becker and Kaufman used qualitative data from 64 subjects over the age of 45 during the first year after a stroke to report that the recovery experience is constructed daily during the course of managing recovery [29]. Survivors often receive vague medical responses to concerns over the uncertainties of recovery. However, they construct certainty on their own in relation to managing the everyday contingencies of living with their disabilities. Many of the difficulties cannot clearly be attributed to the stroke alone, but must be considered in the context of the person's life. Becker found that rehabilitation therapists commonly confound the effects of age with the effects of stroke when assessing stroke survivors [26].

Doolittle described the process by which survivors evaluate bodily recovery following a stroke [33,34]. Over the course of 6 months, she conducted 120 interviews with 13 individuals who had a lacunar stroke. Doolittle presents social psychological processes that patients use to understand the functional status of affected limbs. The patient and caregiver are primary, active participants in managing the illness to achieve recovery and prevent complications. Data revealed that to understand the meaning of recovery in its fullest sense, the researcher must understand what is important and valued by the person. Findings emphasize that treatment strategies need to address concerns of the survivor within their social context.

Another qualitative study analyzed data obtained from books that reported stroke survivors' recovery experiences [36]. Adaptation to changes included agonizing, fantasizing, realizing, blending, framing, and owning. Researchers conclude that healthcare professionals know very little about the actual process of how patients manage recovery after a stroke [33,35,37].

Experience of Time

Time is a salient feature of transitions and plays a significant role in bringing order to one's life and shaping one's sense of self when managing chronic illnesses [38]. Charmaz studied how people manage chronic illnesses and reports that over the course of a chronic illness, a person's self-concept changes and that periods of illness may become significant markers of the chronology of a person's life [8]. She found that people with chronic illnesses often create a linear pattern when describing the course of their illness. Her research supports the importance of the experience of time as a way to understand self-concept and self-development. She argued that interactionists, phenomenologists, and sociologists have largely overlooked the significance of time for shaping the self. By understanding the meanings of periods of time in a person's life, we can develop interventions to assist survivors during the psychosocial transition as they manage changes in the way they see themselves. This preliminary study describes dimensions of the experience of time during the transition and contributes to the psychosocial transition literature on managing chronic illnesses.

METHODS

Data for this study are derived from an ongoing longitudinal study to develop culturally sensitive models of stroke recovery [39]. The local Institutional Review Board and the Department of Veterans Affairs (VA) medical center subcommittee for protection of human subjects approved the study. Stroke survivors and their caregivers were invited to participate in the study while survivors were hospitalized for acute stroke. Informed consents were obtained prior to discharge. Data included in this preliminary analysis were collected during home visits at 1 month after discharge.

Sample

A total of 51 male veterans discharged home with a caregiver after acute stroke are included in this preliminary study. To be included in the study, survivors had to meet the following criteria: (1) ability to communicate as measured by a score of at least 6 on the communication scale of the Functional Independence Measure (FIM), (2) mental competence as measured by a score on the Mini-Mental Status Exam of 18 or above, and (3) presence of a caregiver who was willing to participate. Quantitative

data are used to describe the sample and include demographics, FIM, Geriatric Depression Scale (GDS), and the Frenchay Activities Index (FAI).

All subjects are male veterans with an average age of 64.7 (range of 46–84 years). Thirty-two (63%) are white, five (10%) Puerto Rican Hispanic, and fourteen (27%) African American. Thirty-nine (76.5%) are married and twelve (23.5%) are not married, but all have an identified caregiver. The average age of caregivers is 60 years (range is 40–81). Ethnicity of caregivers includes 32 non-Hispanic whites, 6 Puerto Rican Hispanics, and 13 African Americans. Forty-five caregivers are female and six male. Forty are spouses, one is a son, five are friends, and five did not identify a relationship. Forty-six caregivers are married, one widowed, and five single. Most caregivers have at least a high school education or above (40 or 78%) and live with the patient (46 or 90%). Twenty (39%) caregivers work outside of the home. Approximately one-third (17 or 33%) of the caregivers rate their health as fair or poor.

Type of stroke varies, with 25 (49%) acute, but ill-defined cerebrovascular accidents (International Classification of Diseases [ICD] I 436); 17 (33%) cerebral infarctions (ICD 434); 4 (8%) cerebral occlusions (ICD 433); 2 (4%) intracerebral hemorrhages; and 3 (6%) ill-defined cerebrovascular disease (ICD 437). Twenty-two (43%) subjects have left body paresis (paralysis), twenty-six (51%) have right body paresis, two (4%) have bilateral paresis, and one (2%) have no paresis. Functional assessments (FIM) indicate that most patients are in the high range of functional ability. The average of the total FIM score is 115.6 (standard deviation [SD] of 14.1) out of a possible 126 score. Mean scores are 32.6 (possible score of 35) for the FIM cognitive subscale and 82.9 (possible score of 91) for the FIM motor subscale. The FAI was used to evaluate instrumental ADLs. The mean score is 32.8 (SD 9.9) out of a possible score of 50, indicating a higher level of impairment in these activities compared with the FIM.

Data Collection

Qualitative data were obtained from in-depth, semistructured interviews with stroke survivors, and field observations were recorded during home visits at 1 month postdischarge. Interviews were tape recorded, transcribed verbatim, and entered into N6, a software application designed to assist with qualitative data analysis.

Data Analysis

Analytic procedures began with careful reading of an interview and related field notes to familiarize the researcher with the context of the interview, identify issues and concerns, and identify initial concepts that were used to code the data. Data were entered into N6 and coded. The application assists qualitative researchers with analysis by electronically compiling data related to a code and providing a printout of all data for each code to assist with further analysis. A team of four qualitative researchers analyzed data. As coding of data progressed, researchers identified categories and described the properties of the categories consistent with the grounded theory method [41]. The experience of time is one category. We examined all the data on the 51 subjects related to the experience of time at 1 month postdischarge to identify salient aspects of changes in the temporal order of daily routines, changes in one's sense of self, and strategies that survivors use to manage time during the transition after discharge. Constant comparative analysis reveals that, following a stroke, the experience of time is a significant aspect in the process of transitioning from the hospital to home.

RESULTS

The Experience of Time

All subjects described changes in the experience of time as a dimension of the transition from hospital to home. According to stroke survivors, managing time presents significant challenges during this transition period. We explored the data to determine how stroke survivors experience time in three aspects of the transition experience: (1) changes in the temporal order of daily routines and activities, (2) disruptions in sense of self and the experience of time, and (3) strategies of managing time during the transition period. Data indicate that these changes are tied to functional changes and role participation changes.

Changes in the Temporal Order of Life

Similar to other studies of chronic illnesses, among stroke survivors, the temporal order of their lives (daily routines and activities) is often disrupted. The transition from hospital to home involves adjustments to changes in their usual taken-for-granted ADLs. When asked about changes in his daily life, one stroke survivor notes that his

life has undergone a major change, waiting for assistance to complete daily self-care activities usually taken for granted in assuming responsibility for his own daily care. He states, "Of course, it has changed, because now I have to be in the house here without doing anything and waiting for them [family] to do the things for you. It is very different when you can do your own things." He is 78 years old and suffered lacunar and ischemic bilateral strokes with significant functional impairment (FIM score <5). He describes his declining health as further disruption of simple taken-for-granted activities that create the temporal order of his life saying, "At times I want to put my socks and shoes on and I have to call her [wife] so she can help me." Many survivors describe disruption in routines of daily care, including the inability to shave, button a shirt, put on pants, get out of bed, or take a shower. One survivor who had previously been a cook in a restaurant and suffered a right intracerebral bleed indicates the significance of disruptions in his routine related to ADLs when he states, "Dressing is the hardest, and my bath." Activities as simple as walking into the living room with a cup of coffee cannot be accomplished successfully. He goes on to say that before he had the stroke he would go out with his wife, and now since the stroke they are unable to go out. Another survivor who suffered a bilateral infarct describes changes in his normal activities in this way: "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 may as well stay here [home]." These changes in functional ability are significantly related to changes in the experience of time. Disruption of daily routines is accompanied by a perception of time slowing down, requiring survivors to develop different ways of managing time in the face of physical disabilities and limitations.

During the first month after discharge home, stroke survivors and their caregivers face reestablishing daily routines in the context of changed physical functioning. As they establish their daily routines, they gain a sense of normalcy in their lives. Changes in routines range from remaining in bed most of the time to establishing daily schedules of routine activities such as eating, bathing, and resting, with few excursions into public places. Sam, a 74-year-old man with hemiparesis, had been active doing yard work and maintaining a small farm in a rural area prior to his stroke. He describes changes in the temporal order of his life with the following statement: "Well, I don't rush out there, whatever you feel a little bit like doin', I do . . . I picks up the leaves there a little bit and

set around . . . I am very weak, I do as less as possible, but I am not in the house sittin' down. I stir because I figure that would help me—my body—by using it, but not too much."

Changes in temporal order most often accompany hopes that improvements will come with time. Another survivor, Don, who survived a second stroke and is on dialysis, describes his experience as an increase in idle time when he talks about his typical day since discharge home: "Oh, I'll fool around here, I'm liable to lay down and go to sleep or I'm liable to go out here and goof off, you know, do a little somethin' here or there, little stuff. I don't do much of anything any more."

For some stroke survivors, activities that are important are often significantly curtailed or abandoned altogether after a stroke. These activities were important aspects of their lives prestroke. For example, Jim and his wife, Sandy talks extensively about changes in their lives since returning home after his stroke. When asked what is the best part of the day, Sandy says: "In the morning and at night. He pretty much sleeps all afternoon." Jim then chimes in, "Yeah, so, I just go outside and have me a couple of chews (tobacco)." The increase in idle time ushered in by functional changes poses a significant problem for survivors and their caregivers. Many survivors talk about appreciating time. As one subject says, "Every day that I wake up is a good day." Another survivor's caregiver states, "Time is a blessing." The survivor responds to this statement by saying, "Yeah. Time is a blessing 'cause it really is, because ahh, the only reservation I have at all is not working and producing anything. I mean, that's the bottom line." Surviving his stroke is a blessing, but living with the consequences poses very real losses in role functioning and his sense of himself as a productive person.

An understanding of a person's routine activities requires much more than obtaining a list of common actions at one point in time. Establishing a routine of daily activities is part of learning how to manage at home with functional limitations and abilities. When patients are discharged home, they do not know what they are capable of doing, and an important task during the transition is testing one's limits. As one patient states, "You find something new every day that you can't do." Stroke survivors go through a process of discovering and establishing a routine of activities within the scope of their abilities. When routines are not reestablished, survivors and caregivers experience more chaos and more disruption during

the transition. Caregivers often assume responsibility for establishing the order of daily life. One 59-year-old survivor, who was left with left hemiplegia with a functional level of <5 on the FIM, had not established a daily routine at 1 month after discharge home. His wife sees establishing a routine as her responsibility and is concerned about the daily structure of a routine. His wife shows how others can help get the survivor back into time when she states, "That's something we talked about a little bit, and I talked to a friend about this. I need to get him into a routine." She goes on to describe the transition difficulties, with the ups and downs of good days and bad days, when she says, "It is hard to establish a routine because of how he may feel. On Sunday he had a bad day and I almost took him back to the hospital. When he had this bad spell, it's like you're starting all over again."

Another caregiver of a 65-year-old veteran with expressive communication impairment states, "We just talked last night that we should have every morning to go and walk, you know. Not too far, like if we could just go to a shopping center and walk one end to the other, just the factor that if it's raining or whatever. But just something to get into a little bit more of a routine."

Most survivors are challenged by the tasks of daily life. Formal functional assessment provides numerical outcomes but offers little understanding of the practical implications of being able to perform tasks within the context of their home. Patients judge their functional ability based on how they can accomplish tasks of daily living and engaging in activities that are important to them. One patient states, "I can't do things like I want to do 'em. I gets a little bit shook up, you know? . . . I gets angry at myself."

At 1 month, patients are still very hopeful that function will return and that life will get easier. They test their limits to determine if they can do what they had previously been able to do. It is only in trying and learning in the process that they determine what they can and cannot do, but in this process of transition, the stroke survivors also learn about who they are. For example, one man needed a ramp built so that he could get in and out of his house with his wheelchair. He tried to hammer and build the ramp in spite of serious functional incapacity. In so doing, he injured himself and told us that he learned what he could and could not do by trying to do it. He was proud that he had tried and that he had found a way to give directions to his son who was able to accomplish the task for him. Even though he could not accomplish the

task, he could direct someone else, thereby retaining the "head of the household" role in the family.

A key finding is that the temporal order of one's life becomes disordered following a stroke and is especially challenging during the transition from hospital to home. Partly, this is due to subjects' concerns with increased fatigue and loss of energy that overwhelms many survivors. Frequent naps and rests in bed are used to manage these problems. The daily routine for most subjects includes morning and afternoon naps or rest periods, thus reestablishing order in their lives. Many subjects also describes problems sleeping at night. As one man describes his problems sleeping at night, "I just don't be asleep typically because I nod in the daytime." He goes on to say, "I'm not going to bed so I sit there in the nighttime and just not sleep."

As survivors experience disruption in their usually taken-for-granted daily activities, time slows down because activities take longer to accomplish and there is less activity to fill idle time. Changes also influence one's sense of self as a fully functioning person. Survivors are coping with changes at multiple levels or layers of meanings. At one level is impaired functioning, at another level is slowing of time, and at another level is change in their sense of who they are as people.

Changes in Sense of Self and the Experience of Time

Studies on chronic illnesses have largely overlooked the significance of time in shaping one's sense of self. Charmaz [8] argued that studying the ways that ill people view time offers new ways of understanding self-concept and self-development. Illnesses become significant markers of events in a person's life and people build a new self in relation to the illness. Carl provides an example of this. He describes the impact of the stroke on his life and talked about how this disruption affects his sense of self, stating, "Well, you feel bad but you have to accept it. It was just something that was natural before . . . I would take the car or I would walk in the city . . ." His taken-for-granted assumptions about how he functions in life are altered, and Carl now faces a changed way of being in the world and a new view of himself. Later in the interview, he indicates the significance of his loss: "One's happiness finishes . . . yes, it finishes, what good is someone who is sitting in a chair? It is a bother . . . for a companion, how do you live?" At 1 month poststroke, some survivors are facing the loss of function and are grieving the loss of the old self before they can begin to formulate

a new self. It appears that managing an uncertain self is a hallmark of the transition process.

Glass and Maddox [6] studied the transition following stroke and report that a major illness such as stroke challenges existing assumptions about the identity, self-concept, and role capability. The assumptive world is composed of our interpretations of the past and our expectations of the future, our plans, and our prejudices. For stroke survivors at 1 month postdischarge, one's sense of self is challenged by the disruption in performing these taken-for-granted roles in the family. As one 80-year-old man who survived a small lacunar stroke stated, "Not being able to do the things that I've always wanted to do and loved to do bothers me. It seems as though a lot of my independence, my individuality, has been taken away from me." The world that was taken for granted can no longer be depended on, and stroke survivors are faced with creating new realities in their daily routines and relationships with family and others.

A 74-year-old man specifies his gender by describing his household's clear division of labor. Prior to the stroke, his wife was strictly in charge of the chores inside the house and he was responsible for chores outside the house. This man's perception of his functional ability is influenced by how well he can fulfill his usual role in these outside activities. Defining himself in these terms means that if he is no longer able to assume these responsibilities, he is no longer functional as "the man of the house." Although he might still be able to work inside the home, he views these activities as "woman's work." Fulfilling one's role in the household is one feature of one's sense of self. Howard, a 65-year-old man, describes changes in his role as husband and father when he states, "I feel kind of useless . . . I can't do things for any of my kids, my wife, or neighbors, or anything else." These changes in role function are tied to functional status impairment that prevents him from doing usual taken-for-granted activities in his everyday life. On the other hand, Ralph describes how his physical incapacities and subsequent change in role function create conflicts within his family. He describes himself as usually easy-going, but since the stroke, he has found himself more irritable with his family. He states, "My family may have noticed it [his irritability] 'cause, you know, when they come home, I'm short with them or snap at 'em."

Consistent with Bury's findings, the transition period is a period of disruption, discontinuity, and stress, requiring adaptation and accommodation [7]. Data indicate that the

transition from the hospital to the home is more than adjusting to physical impairments. It is a multidimensional process, requiring changes in the rhythms and routines of daily life, as well as changes in one's sense of self. In addition to these changes, stroke survivors also experience slowing of the passage of time and an increase in idle time, requiring new ways to manage time within the context of their changed functional abilities.

Strategies Used to Manage Time

Managing time following a stroke poses a formidable challenge for stroke survivors. After discharge, activities are often limited and subjects describe ways that they manage time within the context of particular limitations, their family, and environmental situation. Following a stroke, multiple facets of time are affected and create important aspects of the transition from hospital to home. Facets of time that are affected include rates of recurrent behaviors (rhythms and routines of activities of daily living described previously), pace, durations, and intervals of time [41,42]; all coalescing around issues of order, power, self-definition, and knowledge [38]. Most stroke survivors report that their perception of time changes and life moves much slower. From the survivor's viewpoint, strategies to manage time are shifts in the way they would normally experience time. The strategies that survivors use are actions taken in response to the disruption of their usual pattern of living their everyday lives. They describe their actions for managing time as ways to maximize favorable outcomes hoping that with the passage of time their functional status will improve and the quality of their lives will be enhanced.

Most survivors organize their days around eating, napping or resting, watching television (TV), or going on outings if someone can take them. For many, managing time at home is more difficult if they are alone for much of the day. However, most subjects say that a routine to their day establishes a pattern for how they manage time during the transition. Routines help reestablish a sense of normalcy in their lives and help reduce the chaos during the transition. Subjects talk of managing time in three major ways: "passing time," "waiting on time," and "killing time."

Passing time is the most common strategy for managing time used by stroke survivors during the transition from hospital to home. Time-passers believe that the passage of time is a requirement for recovery and that passing time will result in improvement in function. Time-passers

tend not to exert control over their recovery; rather they stated that recovery will come with the passage of time. Passing time could be viewed as a coping strategy for dealing with the negative aspects of living a changed life due to impairments that prevent normal activities.

By far, the most common activity is watching TV. Some survivors watch TV most of the day, while others structure their day around their favorite TV programs. As one man states, "The only thing to do is to watch television." Others describe the best part of their day is when their favorite TV programs are on and the worst part of the day is when there is nothing on TV. Visits from family members are important for passing the time. Other activities that survivors engage in to pass time include using the computer to access the Internet and engaging in hobbies, such as cane making, painting ceramics, or bird watching.

Waiting on time is another common strategy for managing time and is similar to passing time. Both imply a view that the passage of time is required for a change to occur, but the difference is that those who talked about waiting on time also said they did not know what will happen and they are waiting for time to tell. Waiting on time is achieved by sitting on the porch in the rocker, daydreaming, and staring into space. One elderly man describes waiting on time when he states, "So, I'm just idle and waitin' on time. I just sit around and take it easy. I am just waitin' on time. I know it takes time."

Another man talked about managing idle time and his boredom. He says, "To be honest, none of the day is the best part, because I get bored quickly. I used to be active and I get upset when I can't find nothing to do or can't go nowhere, you know, so I just sit here and just meander...my mind meanders backwards and forwards."

In the same vein, when asked about what his life is like now, after coming home from his stroke, Richard states, "I don't have much of a life right now. I sit right here in this damn chair waiting 'till I get well enough to get out and start doing something." He recognizes that the quality of his life is not very good, and that he can only wait for time to pass to be able to resume a more active life.

Another stroke survivor indicates that recovery takes time and that he just has to wait for time to pass to find out how his functional ability will improve. He said, "Well, I have to acknowledge that it takes time. Anything you tell your mind to do, just do or not do nothing, I'm just waitin' on time." Other survivors take a more assertive stance as they talk about another strategy for managing time, killing time.

When survivors talk of killing time, they describe it as a way to get through each day. Killing time is achieved by finding something to keep busy. Survivors used small chores in the yard or the household to kill time. Small chores in the yard include raking leaves, trimming the hedges, and light gardening. For many, assuming chores in the house was a new role, previously viewed as "women's work," and included washing dishes, preparing meals, or babysitting grandchildren. Driving around in the car is also a way that one man describes killing time. Talking about being bored, he says, "Yeah, I just . . . sometimes you know how it gets. I leave out here and go out and drive up there to the post office, drive around to my church, drive around to my brother's. Trying to kill time . . ." When asked what makes his life better, James states that he has a lot of limitations now and that about all he can do to kill time is to take a walk. He says, "Well, walking gives me something to do. Otherwise, I'd sit here in this chair. What would I do otherwise, right?" When talking about the way they spend their days, most survivors describe problems with boredom and not having meaningful activities in their lives. One survivor states, "The worse part of my day is when I don't know what I am going to do to kill the time I have on my hands."

DISCUSSION

The transition from hospital to home following a stroke is a critical period in the recovery trajectory. When stroke survivors go home from the hospital or a rehabilitation center, they have to learn how to manage functional limits within the context of their home and family. The transition process involves three areas related to the experience of time: changes in the temporal order of life, changes in one's sense of self, and the development of strategies to manage time during the transition to fill idle time. Three implications for rehabilitation therapists charged with the responsibility for preparing patients for discharge can be defined from the study.

First, the transition process may be less chaotic if stroke survivors and their caregivers have information about the importance of establishing a routine to their lives after they get home. They need to anticipate the disruption in the temporal order of their lives and to understand that reordering their lives is part of the recovery process that will help to reestablish a sense of normalcy. Caregivers need help in planning to reestablish

routines as a way of decreasing the chaos during the transition period.

Second, caregivers and other family members may benefit from understanding that as the stroke survivor manages the transition period, not only is he/she testing functional capabilities, but one's sense of self is changing at the same time. Family members and caregivers need to support the stroke survivor as old roles are shed and new roles are established. One's self-worth and self-respect hang in the balance as the survivor experiences the losses and struggles to regain participation in a meaningful role in the family.

Third, attention is needed to help stroke survivors find meaningful ways to manage time within the context of their own homes during the transition period. Many survivors will benefit from careful consideration of activities that are available for managing time. Hobbies and interests could be nurtured so that the survivor develops something to do that has meaning in his life. Family members and caregivers need to be encouraged to gradually introduce new or reestablish old hobbies and activities that are possible for the survivor to accomplish.

Future research is needed to develop a multidimensional view of the disruptions due to stroke on the every day lives of stroke survivors and their family and caregivers. We need to more fully understand not only the changes that stroke survivors experience during the transition from hospital to home but also the social and behavioral aspects of the recovery trajectory beyond the transitional period. Survivors, family members, and caregivers need help in understanding how to assist with positive transitions and adaptations following stroke.

CONCLUSIONS

The meaning of time in everyday experience is not as clear as one would expect, given our culture's fascination with temporal accuracy, promptness, and a conception of time that treats it almost literally as a form of money [42]. Changes in relation to the experience of time during the transition period from hospital to home are remarkable and pose significant challenges to stroke survivors and their caregivers. A major challenge is reordering their daily routines into a pattern of activity. Many survivors modify their daily routines to match or fit within the physical limitations resulting from stroke. Others are less stable in the course of their illness and daily fluctuations pose special problems in reordering their lives. The lack

of routine or order is uncomfortable to caregivers, who view establishing order as desirable and part of their responsibility as caregiver. Our data are consistent with Dubinskas' view that time is a fundamental category for talking about orderliness of social life [38].

Many of the taken-for-granted assumptions of daily life are interrupted, requiring assistance in performing daily self-care routines. At 1 month after discharge, frustration is a common response to these changes. Survivors talk about patience and hope for recovering their functional abilities. A salient feature of the transition phase is managing the fatigue and the need for frequent naps and rest periods in bed. Adjusting to changes in the rhythms and routines of life poststroke is closely related to modifications in the selfconcept following stroke. As stroke survivors manage and adapt to their functional limitations, the way they view themselves changes also. Many survivors see this illness as a turning point in their lives, but the outcome or future is held in question. Their immediate task is to find ways to manage their experiences with long durations of "unfilled" idle time.

ACKNOWLEDGMENTS

We gratefully acknowledge the funding provided by the Health Services Research and Development, Department of Veterans Affairs. We appreciate the available resources provided by the Rehabilitative Outcomes Research Center. We also would like to thank the participants for their informative contributions to our ongoing research.

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Submitted for publication June 18, 2003. Accepted in revised form October 31, 2003.