Adaptation to a Stroke: The Experience of One Couple

Lyn Jongbloed

Key Words: cerebrovascular disorders • family • social environment

Objective. Treatment of stroke, as described in the occupational therapy literature, focuses primarily on the person's physical problems, and less on the way in which the family and environment influence adaptation. This article examines family and environmental influences on adaptation to stroke.

Method. The content of five interviews conducted over 2 years with a woman who experienced a stroke and her husband was analyzed with ethnographic research methods.

Results. The analysis revealed that a stroke cannot be understood as an individual phenomenon, because the life course of both the woman and her husband were profoundly affected by it. The man's roles as family member, caregiver, home maintainer, and hobbyist required change after his wife's stroke. The woman's experience of her changed body, dependence, and altered homemaking role were influenced not only by her husband's attitudes but also by societal values.

Conclusion. The findings suggest that clinicians and researchers must pay greater attention to those living with the person who experienced a stroke and to the ways in which the person's social, cultural, and economic environments influence adaptation to disability.

Literature Review

The model of human occupation (Kielhofner & Burke, 1985) was used as a framework for examining the literature on stroke. In this model, human beings are conceptualized as open systems, in whom three subsystems — volition, habitation, and performance — influence the extent to which daily activities can be carried out. By affecting constitutents of skills, a stroke disturbs the communication, process, and perceptual motor skills that compose the performance subsystem. This disturbance, in turn, affects the higher habitation and volition subsystems (Kielhofner et al., 1985). The constituents of skills that may be impaired include attention, concentration, memory, speech, language, vision, range of motion, muscle tone, muscle strength, speed of movement, coordination, and sensation (Finlayson, 1990; Task Force on Stroke Impairment, 1990; Wertz, 1990).

Humans, as open systems, perform in various environments that they influence and that also affect them. The family is one aspect of the environment that has been found to influence adaptation after a stroke and to be affected by the member with the stroke (Evans & Bishop, 1990).

In a review of studies on the effect of stroke on the client and family, Baegel, Sales, Schulz, and Rau (1991) concluded that psychological and social factors, including interpretation of the stroke event and presence of social support, may be as important as physical function in determining the client's quality of life and return to pre-stroke levels of social and work activities. Adaptation is...
related to social support, but no one yet knows how such support affects the course of recovery from stroke or psychosocial adjustment (Evans and Bishop, 1990). Although variables such as family function predict some clinical variables, such as duration of hospital stay after a stroke (Evans, Bishop, Matlock, Stranahan, & Noonan, 1987), clinical variables such as the functional capacity of the client with stroke do not have much effect on family functioning (Evans, Bishop, Matlock, Stranahan, Smith, & Halar, 1987). Such findings suggest that family variables may influence clinical ones more powerfully than the reverse.

Furthermore, stroke has been shown to affect the client and caregiver differently (Biegel, Sales, Schulz, & Rau, 1991). Caregivers usually have a higher than normal chronic anxiety level (Evans, Noonan, Bishop, & Hendricks, 1989). Additionally, being married to the client, being female, and experiencing declines in standard of living or confiding relationships are related to higher levels of caregiver depression (Biegel, Sales, Schulz, & Rau, 1991).

Studies on the effect of a stroke on clients and their families have been primarily quantitative (Bishop, Epstein, Keitner, Miller, & Srinivasan, 1986; Evans, Bishop, Matlock, Stranahan, & Noonan, 1987; Evans, Matlock, Bishop, Stranahan, and Pederson, 1988) and have used a priori categories to present and examine findings. The ways in which family members shape the experience, goals, and activities of those who have had a stroke have not been well described or analyzed. Little is known about the influence of family members on altered roles and activities after a stroke from the perspectives of the person who experienced a stroke and his or her spouse. Additionally, longitudinal studies of clients and caregivers are rare, thus there is little information available on the ongoing process of adaptation, in which other factors and issues may supplant those that were most important immediately after the stroke.

Studies on stroke in the occupational therapy literature emphasize treating performance deficits of the client to increase independence in activities of daily living. They have not stressed the influence of the family or environment on clients' adaptation to stroke. Of the 131 articles on stroke published in 11 occupational therapy journals between 1970 and 1992, only 8 articles addressed environment-related issues such as the family. Yet studies outside the occupational therapy literature have suggested a strong relationship between adaptation to stroke and a variety of family interactional and psychosocial variables. These studies point to the importance of exploring the ways the family affects, and is affected by, the member who experienced the stroke, from the perspective of the persons involved. In-depth analysis of how family members are influenced by the stroke and how they, in turn, affect the maintenance or alteration of roles and activities of the member with the stroke, will assist in identifying ways in which therapists can facilitate adaptation to a stroke.

Method

The case study presented here is taken from a larger qualitative research study on adaptation at home after a stroke. In that study, 20 couples were interviewed in their homes. One partner in each couple had experienced a stroke. The subjects with strokes were recruited from five hospitals in the Lower Mainland of British Columbia. Criteria for inclusion in the study were functional problems (e.g., difficulties performing some daily activities) after discharge from treatment, an age of 55 years or older, absence of cognitive problems or aphasia, being unemployed at the time of the stroke, an ability to communicate in English, and a partner willing to participate in the study.

During the 2-year study period, 5 couples were interviewed five times, 13 couples were interviewed four times, 1 couple was interviewed three times, and 1 couple was interviewed twice. Couples who were interviewed fewer than five times generally had regained stability in their lives at the time of their last interviews, so further interviews were considered unnecessary. The interviews were conducted by myself, another researcher, and a research assistant who each followed a proportion of the 20 couples for the duration of the study. A semistructured interview was used to elicit issues of most importance to each person. Participants were asked to describe their lives since the stroke, the chief problems the stroke had caused, and how the stroke had affected their activities, roles, and relationships. Later interviews focused on problems identified in earlier interviews. All subjects (clients and partners) were interviewed alone, and every interview was recorded on audiotape and transcribed. The researcher also recorded her observations immediately after the interview.

Intermeshing of data collection, analysis, and problem definition is an integral feature of qualitative research (Glaser & Strauss, 1967). The three researchers discussed and identified emerging themes from the interviews they conducted and then organized the themes into categories (Hammersley & Atkinson, 1983). Each researcher then coded transcripts of interviews she had conducted. Six transcripts were coded independently by two of the three researchers and then checked for consistency. Extremely high consistency in categorization was found among the researchers.

This article presents the analysis of one couple's experience. The couple was selected because their case best illustrates certain themes identified in the larger study and best portrays the effect of various aspects of the environment on a person who experienced a stroke and his or her spouse. The case forms part of the analysis; it is not intended to result in generalizable findings (Mitchell, 1983).
Case Study

Background

The couple consists of a woman aged 55 years, with a right cerebrovascular accident, and her husband, aged 61 years. They were visited in their home on five occasions, namely 5, 9, 14, 20, and 29 months after her stroke. The woman's treatment included 2 weeks of hospitalization, outpatient physical therapy and occupational therapy once a week for 6 months, and three follow-up visits to physiotherapy and occupational therapy approximately 3, 6, and 9 months later.

Occupational therapy intervention with this woman focused on visual assessment related to regaining her driver's license, management of her subluxed shoulder, and regaining function of her impaired arm. She expressed satisfaction with the therapy she received and the encouragement given to her by the occupational therapist. The couple reported that the occupational therapist did not explore how the stroke had affected their roles.

According to her medical records, 3 weeks after the stroke the woman was independent in activities of daily living (indicated by a score of 100 on the Barthel Index [Mahoney & Barthel, 1965]), was developing synergies in her impaired upper and lower limbs (indicated by a Brunnstrom stage of recovery of 2 [Brunnstrom, 1970]), could walk independently without aids, and had unimpaired cognitive function (indicated by a score of 30/30 on the Mini-Mental Status Test [Folstein, Folstein, & McHugh, 1975]). Eight weeks after the stroke, results on the Sensory Integration Test (Jongbloed, Collins, & Jones, 1986) showed that she had a discrete deficit in the upper left visual field. No other problems were noted.

Individual interviews with this couple revealed that they had been married for 35 years at the time of her stroke and had two married sons (aged 34 and 30 years), each of whom lived within 40 kilometers of them. The home and the family were the central components of the client’s life. Her ability to cook had always been important to her, both in making family dinners and in her role as homemaker. Before her husband’s retirement, which had occurred 6 months before her stroke, when he was 61 years old, she did volunteer work at a local hospital and also met with friends. Her husband had been president for 43 years of a large chain of stores with 6,000 employees. For many of those years he had worked 16- to 18-hr days, 7 days a week. He was accustomed to being in control and doing things his way. He was task and achievement oriented. He said:

I think I’ve always been very selfish about my time, to utilize every minute of every day. It’s the nature of the job man I was in. And that just sort of carries on. I’m going heckly split from 6:30 in the morning. I can’t go to bed at night unless I accomplish something.

He had looked forward to retirement as a time when he could travel.

Findings

The stroke affected this woman and her husband in different ways. For the woman the stroke affected her body, her experience of dependence, aspects of her homemaking role, and the way in which her husband attempted to control aspects of her life. For her husband, the stroke primarily affected his ambitious retirement plans. His reaction to downsizing these plans, as well as to the alteration in roles after his wife’s stroke and her increased dependence, appear to have strongly influenced his wife’s experience of disability. Thus the four main themes that were identified from the interview data were the dysfunctional body, dependence, role change, and alteration in retirement plans. Except for the latter theme, these themes were also identified by the other subjects of the larger study.

The dysfunctional body. A stroke was an assault on the client’s body. The onset was acute, followed by slow recovery and, finally, stabilization at a lower level of functioning than before the stroke. This woman found that her body parts were no longer compliant instruments that carried out her intentions. She stated the following:

And like the shoulder. I do everything with this clumby arm, trying to strengthen it and it’s been 8 months and it’s been blooming sore. And you can’t sleep properly or you can’t rest properly, because you turn on it and you’ve got to lift it up and move it. And then I work on my hand all the time. And I try to hold something in this hand and this hand won’t work. I can’t pick up anything in it and I just get so frustrated.

Learning to cope with the loss of control of bodily function was difficult for this woman. She and her husband assumed that the more therapy she received, and the harder she exercised, the more she would regain normal function and reverse the effects of the stroke. They believed that medicine and therapy were extremely powerful. As she stated, “I think in my mind . . . if I do everything they tell me to do, everything’s going to be okay. I know I’m going to get it all back. I’m just determined.”

This woman’s view of her body was also influenced by her husband, who encouraged her to practice walking. She described the process this way:

I said, “Oh, my leg’s sore.” And he said, “Well, get out there walking.” So, I thought, okay, do more, must be because I’m not doing enough, do more. So, I was up to 2 miles a day.

Her husband initially viewed the stroke as a temporary setback, after which they would once again have their lives back “on track.” In describing the way in which he encouraged her to practice walking, he said, “I hounded her to get walking. ‘Let’s get things going, get your muscles toned back so we can do things.’”

She persisted in walking long distances (2 miles) despite the pain in her leg. Later, her physician pointed out that the pain was caused by pressure on the sciatic nerve and that the amount of walking she was doing exacerbated the pressure.
Over time, it became clear to her that hard work and exercise were not resulting in improvement in function and this realization led to disappointment and frustration.

I've done everything they've told me to do. Everything! And I still haven't got any better. And I haven't got my arm any stronger. I do about 35 different exercises 40 times a day each. And I've kept that up for over a year.

And I realized, oh, my God, that's all they can do. I guess we're brought up to think, okay, you're sick, you go and you get fixed. Well, this, it's a sickness, sort of thing. I want to be fixed, but you can't be fixed.

The beliefs of this woman and her husband about the power of medical treatment and the value of exercising hard were similar to those of many other study participants. In North American culture, perseverance is valued. People believe that if they try hard, they will succeed in overcoming all obstacles (Phillips, 1985). This work ethic extends to clients' understandings of rehabilitation. That ethic spurred many subjects to put much effort into therapy. They also expected that the more intervention they received, the more they would recover function. The work ethic and the attitude that more is better epitomize a Western cultural assumption, that through training and perseverance, disease can be mastered and the negative outcomes of disease reversed (Gordon, 1988). However, perseverance, at least in this client's case, did not reverse the outcomes.

**Dependence.** After her stroke, this woman was dependent on her husband for help with tasks that could not be done with one hand (e.g., putting produce into plastic bags in the grocery store). She commented on the effect of having to ask for help:

I never realized how independent I was until this happened. I used to do what I wanted when I wanted, but now I have to rely on somebody for help all the time, and you get very tired of asking people to help you.

She expressed frustration that her husband could not anticipate the help she needed:

I want help, but I just wish I didn't have to ask. Which is hard for him, because he doesn't know. He hasn't been programmed to be honest, men are not like women. My sister-in-law will be here, or a friend. They see me going to do something and they know I'm going to have trouble with it —like mother and child —they go right over and they start to help me. Where with a man, they'll look and they'll watch you sit and struggle and struggle... And it's not that they want you to be independent. It's just that they don't realize, oh, she needs help with it.

In contrast to many women in this study who automatically reduced their own activities in order to care for and transport a partner with a stroke, this man expressed frustration about having to interrupt his activities to drive his wife to various locations in the 10 months after her stroke. He said, "I should be able to say, 'Well, fine.' And I drive her, but I usually seem to make the point that it's putting me out, that it's inconveniencing me." She expressed her feelings regarding her dependence on her husband for transportation in this way:

I have to rely on him or ask him, you know, and he won't take me places if he doesn't feel like doing it. He says, I'll do it next week. You not only lose control of yourself [after a stroke], you lose control of what you did in your life. And it's very frustrating.

Ten months after her stroke, the woman regained her driver's license and this made a tremendous difference to them both, in that her husband's activities were no longer interrupted by having to transport his wife to various places and she regained some independence.

Although changes in the body after a stroke can themselves diminish a person's sense of self, it was the effect of these changes on relationships at home that really characterized the changed situation of this woman, as well as the situations of other clients in this study who had had strokes. In Western culture, dependence is generally viewed negatively. Dependence implies weakness, whereas independence implies strength and responsibility (Williams, 1984). However, dependence cannot be viewed as an individual attribute. Family members are interdependent. The challenge after a stroke is not that there is a change from independence to dependence in daily activities, but that the normal patterns of interdependence are disrupted and new patterns have to be renegotiated (Williams, 1984). The shift in this pattern, often made tangible in having to request help from others, was disliked by subjects with strokes in this study, both because they experienced a loss of control and because this placed burden and constraint on others.

The effect of societal values on attitudes to caregiving was evident in comparison of the ways in which the men and women in this study reacted to the additional obligations of caregiving. Attitudes to caregiving are not innate; they are culturally created (Borsay, 1990). Although women may resent additional obligations, they have been socialized into a caretaking role. A husband with a disability means more work, but it is not a dramatic change from the standard practice of caretaking (Borsay, 1990). On the other hand, when a woman becomes disabled, her partner is faced with roles and demands that are unfamiliar to him (Borsay, 1990). Most female caregivers in this study readily assumed additional work and reduced their own leisure activities because of their husbands' disabilities to perform certain activities of daily living. The husband in this case, on the other hand, viewed requests for help as intrusions on his activities and resented the intrusion.

**Role change.** Before her stroke, this woman was responsible for paying bills; washing clothes; ironing; bed making; food shopping, preparation, and clean up; and hosting frequent family dinners. A housekeeper cleaned the house once a week. Her husband was responsible for the garden. Shortly after her stroke, he assumed responsibility for making the beds, washing clothes, food shopping, and cooking. Over time, she resumed responsibility for washing clothes, helped with the food shopping, and prepared a simple breakfast and lunch; her husband...
cooked the evening meal. Family dinners still occurred after her stroke, but less frequently, because she could no longer prepare dinner independently. Defined roles became blurred after the stroke and this resulted in considerable role conflict. The husband expressed it this way:

In our age group, men and women have defined roles. Now it's more difficult for both of us because they are blurred. Once time I would've just worked outside and done all the things that the old days a man used to do. She took care of everything in the house. There was no question of whose domain was whose. And I never interfered, of course, with anything she did. She was very proud of how she kept the house and she lost that when she saw me getting in there and doing those things. That was a tremendous blow to her mentally. I'm sure. And so we are at loggerheads. But, at the same time, these were not things that we could just forget about. I mean, the meals had to be cooked, the beds had to be made, the washing had to be done.

The main tension created by the stroke was around food and cooking tasks, part of the homemaker role. The woman could no longer manage all the tasks involved in cooking the evening meal. Her husband could have assisted her to maintain this valued role by performing those tasks she found difficult (e.g., peeling vegetables). He was, however, unwilling to do this and stated his position in this way:

I'm very strong willed, and I think when I do something I want to do it all myself and I want to do it the way I want to do it, and I want to do it quick. And I'm not too diplomatic about it. When I want to make dinner, I have definite plans of what I want to do and I do it. I just simply do it. If I was a different person, I think, it would be much easier for her, too. I don't like someone saying, you know, 'I'll do this, while you do that.' I want to do it, making her meal preparation role by performing only those tasks that she could not do. Loss of this role was more difficult for her than any other loss after her stroke, influenced to a minor extent by physical disability and to a major extent by her husband's response to the situation. Rather than help his wife resume her meal preparation role, he assumed control in the kitchen.

As Borsay (1990) pointed out, the traditional division of labor may be overturned by disability in marriage. The gender of the person with the disability is critical. "Kinship bonds vary in their resilience to disability according to whether transfers of assistance fit the normal transactions of family life" (Borsay, 1990, p. 114). Caring works best when gender and kinship roles are left intact (Borsay, 1990), as they would be if a child or male partner experienced a disability. Before retirement, 6 months before his wife's stroke, this man's main contribution to the family had been financial. He had to adapt to retirement and his wife's stroke almost simultaneously. The role of caring for his wife was foreign to him. In this case, gender roles were not left intact. This man performed his new homemaking role efficiently, but his unwillingness to allow his wife to do tasks she was able to do was difficult for her to cope with.

In this study, most subjects who had had strokes felt a sense of loss related to incompetence or inability to perform, various roles after a stroke. How losses were experienced was influenced by factors such as the importance of the role to the person, the person's functional status (e.g., ability to drive or climb stairs), the physical environment (e.g., stairs, bus service) and the response of the partner to the role changes (e.g., willingness to drive, willingness to help the partner with the stroke.
maintain his or her roles). Many partners in the study had to assume one or more roles with which they were unfamiliar (e.g., financial planning, home repair and maintenance). Responses of partners to such role changes were influenced by factors such as gender, personality, and the quality of their relationship with their spouses.

Alteration of retirement plans. The client's stroke altered her husband's life. She described its effect on her husband's travel plans as follows:

Well, it's really changed his whole life. He worked for 43 years in one company to get this retirement. He really wants to do a lot of traveling and I said, "There's just no way." There's just no way that I can. I mean, I'm pooped even hanging around here.

The man had trouble altering his plans. Initially, his reaction was as follows:

There's no way we're going to quit. She's uncomfortable with the thought of going on some of these trips, but as soon as she gets one or two under her belt, I'm sure she's going to be okay. I think we're just going to take a year off our life and then we'll get back on track again.

Later on, however, he realized that his plans for travel in Asia and Africa might never materialize:

And I guess what settles in is that we really have had a life-style change and that it's going to go on for the foreseeable future. When it first happened, I thought that this I just go on for a short time. We had planned for many, many years and we had worked hard toward these goals. And it's a major change or major setback. And every time I see somebody in hospital that's in very bad shape, I think to myself: I should feel lucky. And then I look around and see my friends that are out doing things and haven't any problems at all, and I say to myself: "Well, shoot, we're not as bad off as those folks in hospital, but we're certainly a lot worse off than most people our age."

This couple was able to do some traveling. They traveled in a camper to the southern United States, but this proved tiring so they sold the camper and, on a subsequent trip, rented a condominium. What they were forced to give up was travel to such locations as Asia and Africa. The husband commented on his anger about this and how it affected his relationship with his wife:

I think we handled it better at first than we do now. And it's probably because there was an end to it. When I don't think, I get impatient. I mean, that's cruel and that's something I mustn't do. It's certainly not her fault that she had a stroke. I don't think of it as being angry with her, but it comes out the odd time as being angry with her when I just feel frustrated and angry.

His wife expressed her feeling this way:

He and I have been having a really hard time lately. We're not getting on. We're at each other and I know it's out of frustration. He doesn't blame me, but he can't help thinking if it wasn't for this, which is me, that he'd be able to get on with his life. And with me, I just feel guilty all the time. I've ruined his retirement, his trips, his planning.

During a final research interview with this couple, 2½ years after the woman's stroke, the man indicated that he was getting used to the idea of less travel: "And if I can't travel, then I can't travel. I mean, I could have been the one that was sick and couldn't travel. So, maybe I wasn't meant to travel."

Recent major renovations to their house, which he had planned and overseen, as well as participation in a flying course, had consumed much of his energy in the previous 6 months.

Bury (1982) conceptualized chronic illness as a major disruptive experience. A stroke disrupts the life of the person who experienced the stroke, as well as that of the partner. According to Biegel, Sales, and Schulz (1991), family life stage has a major effect on the reaction of family members to illness. Childhood socialization leads members of a society to anticipate certain events at particular times in their lives. When peoples' lives conform to age-related expectations, they can prepare for expected changes. They also have the support of others in their age group who are undergoing similar transitions. When such events occur at unexpected times, persons may not be prepared for them, or may not have others with whom to share their difficulties. Consequently, adaptation may be more problematic. Spouses may be best able to cope with illness and disability in later years, when these are anticipated. Family members are not socialized to expect caregiving responsibilities for their spouses in their younger years (Biegel, Sales, & Schulz, 1991).

Because this couple was relatively young when the client's stroke occurred, the stroke was an enormous shock to them. They had anticipated being healthy, being able to maintain the roles they were accustomed to, and being able to travel. Though family members and friends were supportive, no friends their age were experiencing similar difficulties. They consequently felt worse off than most people their age. Couples in the study who were older were more accepting of losses and stated that strokes and other chronic and disabling illnesses were not unexpected at this time in their lives.

Discussion and Implications

This case study has been used to exemplify how the restructuring of life after a stroke has to be viewed within the circumstances of the lives of both the person with the stroke and his or her partner. In occupational therapy, as our literature reveals, we tend to conceptualize the problem for the person with a disability as dependence in daily activities. In response to this, we aim to restore ability to perform tasks independently. However, this approach is limited because it views dependence as an individual characteristic rather than the quality of relationships between people. In emphasizing that the person with stroke become self-sufficient, this approach ignores that person's existence within a network of relationships. The focus on the decontextualized person underplays the dynamic nature of the experience of disability and the influence of the social situation in which it occurs (Williams & Wood, 1988). Occupational therapists must understand each person's experience of disability and how it is
shaped by personal, socioeconomic, and political context and the forms of knowledge that underpin them are disrupted” (p. 169). The person is then faced with a major restructuring of life; this is not a static phenomenon, but an ongoing process that is shaped by personal, socioeconomic, and political context (Williams & Wood, 1988). The couple described above experienced disruptions in roles and in their perceptions of who they were and what they were able to do. The restructuring of their lives was influenced by the wider socioeconomic system. Family life is part of the economic system and kinship incorporates a set of “contracts” between different genders and generations who carry out the family’s socioeconomic functions (Borsay, 1990). For the woman in this traditional nuclear family, inability to prepare a meal independently had symbolic significance because of her position as homemaker within the domestic division of labor. The disruption of her role undermined the web of meaning that gave coherence to her everyday life (Heller, 1984).

Attitudes of caregivers are also shaped by kinship bond and gender (Borsay, 1990). The women in the larger study viewed caregiving for partners with disabilities as a natural extension of their normal role. The caring role is a secondary feature of men’s lives, even when there is disability in the family (Williams & Wood, 1988). This fact was illustrated in this case study, where the man’s reluctance to play a nurturing role was influenced in part by the fact that men are not socialized into tending roles. He was not skilled at playing a nurturing role, nor did he value this role. If he had been willing to do only those cooking tasks that his wife could not manage, she would have been able to maintain a feeling of competence in performance, despite her disability. This case illustrates that although people can make all sorts of adaptations at home, the extent to which these efforts are successful is not independent of their place in the wider socioeconomic system.

The meaning of the stroke for the person and his or her partner emerges over time as specific aspects of the condition are experienced. These experiences do not often occur until after discharge from the inpatient rehabilitation setting. Consequently, the family will have to face new challenges without formal support from health professionals. Although occupational therapists prepare clients recovering from stroke for changes related to decreased physical abilities, the therapists could spend time preparing couples for the many other challenges that may lie ahead. They could discuss potential changes in everyone’s roles, activities, and future plans, and explore possible feelings related to such alterations. They could set up group discussions, including couples who have already made changes in roles and activities after a stroke and are willing to openly discuss their successes and failures. Although stroke support groups are designed to address some of these issues, not all persons attend such groups after discharge. Therefore it is important to address these issues during occupational therapy.

Outpatient or home follow-up visits are other means for providing professional support. They can be used to discuss the family’s handling of its changed roles and resulting problems and how the member who had a stroke might be helped to resume his or her place in the family unit.

Conclusion

Reactions to a stroke are the combined result of physical, subjective, and environmental influences. The relative importance of each and the relationship of one to the other differ among persons and can be understood only by a close study of each family. This article described and analyzed some of the ways in which a stroke affected the lives and plans of one couple. The man’s roles and retirement plans required change after his wife’s stroke. The ways in which he responded to these changes, in turn, influenced his wife’s experience of dependence, reduced physical function, and altered roles.

A stroke requires a major restructuring of who one is and what one is able to do. This restructuring is an ongoing process, shaped by personal relationships and the sociopolitical and economic context. People actively create and respond to the environments that both enable and constrain them. The dominant professional view of stroke and its consequences emphasizes difficulties associated with physical disability. However, the physical and social circumstances surrounding a person at home after a stroke will likely influence him or her in more profound ways than the ability or inability to perform a number of tasks independently. The threats to autonomy presented
by chronic disability have to be viewed in relation to this
totality, which is molded out of the circumstances of daily
life. The person's goals and interests and the unique charac-
teristics of his or her environment must be understood.
Only in this way is it possible to understand the dilemmas
and challenges that persons with strokes confront and
their influence on occupational performance. Conse-
sequently, occupational therapists must give greater atten-
dtion in research and intervention to contextual factors
such as family relationships and the social basis of moral
rules regarding caregiving. The ways in which gender and
beliefs about division of labor underlie daily activities re-
quire research Occupational therapists could also ex-
hibit a continuing dilemma.

**Acknowledgments**

I thank the other investigator of this study, Sue Stanton, M. of
the School of Rehabilitation Medicine, University of British
Columbia; Barbara Fousek, M.A., the research assistant; and Jacque-
line Maxwell and Jean Kwong. I also thank the people who
volunteered to participate in the study, and Isabel Dyck, R.N.,
who reviewed a previous draft of this manuscript. I thank Patri-
cia Bustomonte, Sandra Caverly, Susan Louie, Megan Marshall,
Karen Mills, and Chris Wood for recruiting subjects for the
study, and Dawn Daeschel, Brigit Duckworth, Barbara Haf,
Brenda Robinson, and Yewna Mansfield for their support of the
project.

The research on which this article is based was funded by a
grant from the British Columbia Health Research Foundation.

**References**


Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). Mini-


egan Paul.


Task Force on Stroke Impairment. (1990). Symposium recom-
mendations for methodology in stroke outcome research. Supplement to Stroke, 21, 9, II 68-73.

Wertz, R. T. (1990). Communication deficits in stroke survi-


