

ILLNESS EXPERIENCE AND BRAIN DAMAGE: A NARRATIVE WINDOW ON
STROKE AND ALZHEIMER'S DISEASE

by

CAROLINE SCROOBY

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SUPERVISOR: MR R.A. BUTCHART

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SURVIVORS

For years I've watched
an old mesquite tree -
gnarled and bent and twisted -
buffeted by winds and droughts.

It started to grow up
toward the sun and sky.
But the soil is so poor,
the water so scarce,
the heat so fierce,
so cold at times,
it was beat to the ground.

Each Winter you'd think,
- it's dead, for sure!
It's succumbed to the odds
stacked against it.

Yet wait 'til the Spring
and a miracle occurs,
New life springs up
from the gnarled old branches -
a tiny chartreuse sprout
heads straight for the sun!
It lives - overcoming
all that is hard,
telling all the world,
- I live, I will survive!

Sometimes I feel like that old mesquite tree
I feel battered by life's adversities,
I feel down - but not out!
When Spring rolls around,
I feel a fresh stirring of life.

I have things to do -
places I want to explore,
people I love!
I can hold my head high -
look the world in the eye -
and say,
- I live, I will survive!

Maude S. Newton (Caregiver of
Alzheimer's patient, in
Gruetzner, 1988, p. 142)

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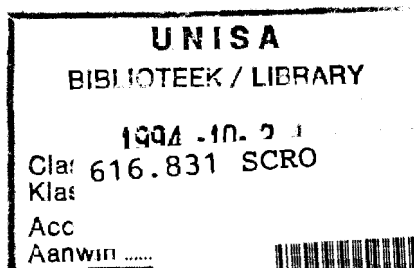


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SUMMARY

In recent years, the move toward a more holistic perspective in health care has led to social scientists investigating psychosocial factors in chronic illness, such as the different languages used by health professionals when talking about nonhealth. However, there has been little inquiry into caregivers' illness experiences of stroke and Alzheimer's disease (AD). This study therefore explores the illness experiences of seven caregivers whose spouses are stroke or AD patients.

A hermeneutic approach was adopted and two relatively unstructured interviews were conducted with each caregiver. Using Kleinman's work on illness narratives as an interpretive framework, it was found that - except for people questioning the authenticity of AD caregivers' experiences - similarities in caregivers' experiences outweighed differences. All described the extent to which their lives had been damaged by the illness and their reparation attempts. Critique of the research is presented and the findings' implications for treatment are suggested.

CHAPTER 1

CONSTRUCTING THE WINDOW

The Surreptitious Pursuit for Diagnosis

Eventually I told my house doctor and we got him to a neurologist and the neurologist said, no, he doesn't see any signs of Alzheimer's. He sees a gentleman of 60 odd who - (we have a son who, is also not well. He has a drug-induced schizophrenia and has given us a lot of grief and heartache over the years. So, my husband always blamed all his problems on the fact that he had all this grief with our son). So, he said, "no", the neurologist said, "No, there is nothing. I don't see anything, he is just deeply stressed about the son and that's that". I thought to myself - no - (a) I thought he doesn't want to work and (b) I thought my husband has still the ability to cover up nicely ... this was his wife who was just imagining ... In that period we struggled along ... Then we went to see another doctor and then I got clever and I wrote out what I had noticed. I wrote it all on a fullscap sheet, all the things I had noticed, and I surreptitiously gave it to the doctor and he read it and he went to examine my husband and he came out and said: "No, there is no doubt what it is, it is Alzheimer's and I'm very sorry bye-bye". You know,

doctors, I don't know whether you have heard this, but the doctors are impossible. They can't do anything and they really don't want to. I think they're frightened. They know they can't do anything and they feel impotent. They feel totally impotent ... So then, I think now and then my husband would say: "God, what is the matter with me? I can't remember anything!" Then we went back to the original doctor; the original doctor who had said there was nothing wrong with him ... and the diagnosis was made. And he put him onto all the usual crap that doesn't help one little bit and we used to go every three months. He would say, "Hello", and he would say to me, "How is he?" - "How are you, Mr P?" So, you know, it was just a routine sort of thing ... And then, about a year ago, I suddenly noticed he can't speak nicely; the words are not coming out. So, I spoke to a friend of mine who is a speech therapist and I said, "What is, you know, going on?" and she explained and she sent us to a very nice young speech therapist. And I must tell you that the speech therapist has taken more interest in him, has done more for him, has been more supportive than any of the neurologists. She's the only

one who has really shown - so, then, she asked us to go to another neurologist who she said is very speech orientated and we went and he is indeed a very dynamic young man. But, even he said: "Terribly sorry". He is very interested in the speech centre of the brain where he can help, but he said there is nothing he can do. "But, by all means, if you feel like it, do come back and see me". So, we haven't been to see any doctors lately. (Cynthia P., caregiver of Alzheimer's patient. First interview, 8 July 1992)

The Vigilant Detective

I feel that the neuro should have taken notice of what I had observed. After all I have lived with him for years and I know how he reacts and what he looks like and what he does, but he wasn't interested. So, then, once he had what they call a stroke, he (the neurologist) said that was the first stroke he had had. But, it wasn't! I was at the hospital all the time, because I wanted to see what was going on after this churlish treatment from the neuro. When I left him (her husband) he seemed to be okay. Then the next

morning early when I 'phoned, I just 'phoned to see how he was, and they said, "Oh, he had a good night", and the nurse sounded, I don't know, there was something about her voice. So, I said, "Well, look, if there is any change I want you to 'phone me please". So about five minutes later they 'phoned to say would I please come up to the hospital. Now, there again I felt there's no communication. Why did she tell me he was all right, when she knew damn well he wasn't? (Ann Z., stroke caregiver. First interview, 5 June 1992)

These extracts conjure up images of two women, both simultaneously the wives and primary caregivers' of their ill husbands, repeatedly attempting to penetrate an invisible barrier between their own and the doctors' perspectives about their ill husbands in a search to be heard, understood and helped by medical professionals. Cynthia P., whose husband is an Alzheimer's patient, tried to break down this barrier by "surreptitiously" giving the second neurologist a fullscap sheet of paper with her observations. Her experience of their encounter with the first neurologist was dissatisfying, because her husband convincingly conveyed the impression that she was "just imagining" that he was ill and that his problems were

merely due to the "grief" and "heartache" he had experienced over the years with his son's illness. Not only were her observations disqualified, but she and her husband had to "struggle along" until such time that she became desperate and "got clever" enough to devise a plan of getting through this barrier to be heard by the doctor. The manner in which she describes their encounters with the neurologists reveals a sense of frustration ("the doctors are impossible") and despair at both the hopeless situation and the apparent helplessness experienced by doctors ("they can't do anything ... they're frightened ... they feel impotent"). She thus reacted to the doctor's post-diagnostic treatment attempts with disdain and anger - "put him onto all the usual crap that doesn't help one little bit".

Ann Z., the wife of a stroke patient, also describes being disqualified by her husband's neurologist ("he wasn't interested") and when relating the incident during the interview spoke emphatically and was indignant about what had transpired. She thus felt it was necessary to be present at the hospital as much as possible ("I was at the hospital all the time, because I wanted to see what was going on") in the hope that she might gain some idea about the doctor's perspectives. When she was not present at her husband's bedside she would telephone the hospital and listen carefully to the changing

nuances in the nurse's voice to try and detect any changes in her husband's condition. She neither trusted the nursing staff to call her if there was a slight change in her husband's condition nor to reveal their perspectives on his condition when she contacted the hospital. Instead she felt she had to be acutely vigilant in an attempt to detect whatever subtle clues as to her husband's condition might be present in the doctors' and nurses' speech and behaviour. However, Cynthia's strategic approach and Ann's undercover detective method did not succeed in removing the impervious, invisible barrier between the illness experiences of caregivers and the language of disease created by medical professionals (Kleinman, 1988b), because even once a diagnosis was made by the doctors these women felt disqualified and unsupported. Ann explained that she "felt there's no communication" and Cynthia reported receiving more support from a "very nice young speech therapist" than any of the neurologists.

Neglect of the illness experiences that patients' and their caregivers' bring to health professionals, is one outcome of the practitioner's adherence to the biomedical model.

In the practitioner's act of recasting illness as disease, something essential to the experience of chronic illness is lost; it is not legitimated as a subject for clinical concern, nor does it receive an intervention ... Hence, at the heart of clinical care for the chronically ill - those who cannot be cured but must continue to live with illness - there is a potential (and in many cases, actual) source of conflict. (Kleinman, 1988b, p. 6)

In the case of Cynthia and Ann, the conflictual nature of their encounters with various doctors is evident in how they narrated these encounters. For instance, Ann felt angry about what she construed as the nurse's deception - "Why did she tell me he was all right, when she knew damn well he wasn't?", and the "churlish treatment" she received from her husband's neurologist. These experiences served to encourage her insistence that she be heard and informed about diagnostic and treatment decisions.

A metaphor one could use to describe the inaccessible nature of health professionals' esoteric language, is that of a one-way mirror between them and their patients. The professional is able to see the patient through the mirror and can make hypotheses based on his observations and what the patient says. However, the patient sees only her own reflection

and thus gets no meaningful feedback concerning her illness. The health professional is therefore at a metalevel to the patient, which enables him to select and transform the information given by the patient and to make deductions from his external frame of reference. The patient, on the other hand, has only limited influence over this transformation and is left alone to make sense of those experiences not considered by the practitioner. This disjunction can have both positive and negative consequences. A positive resistance can be induced, which strengthens the patient's decision to overcome the illness or, on the other hand, it could reduce the patient's receptivity to useful medical information.

The metaphor can be extended to include the experience of caregivers. In recent years, the demands upon the family caregivers of adults with chronic illness have become increasingly complex due to the large decrease in mortality from acute diseases following advances in surgery. A second contributing factor is that economic pressure has led to a number of changes in the health and social service systems that have put additional pressure on family caregivers. In view of these

factors, it is clear that caregiving research, which has developed along two major streams - the effects of caregiving on the caregiver and interventions to address caregiver and patient needs - should become a more focal area of research in the future. However, Kleinman (1988b) points out that thus far, although "there is much to admire and recommend in current medical practice, the care of chronic illness is not one of the great success stories of contemporary medicine" (preface). Underlying this failure in the care of chronic illness, is the model of disease that informs the gaze and practice of medical practitioners. While this model locates disease deep within the body, thereby enabling the diagnosis and treatment of physical lesions, it by the same token diverts attention from the domain of the social and semantic, thus contributing to the conflictual situations described above.

Since, broadly defined, "a model is nothing more than a belief system utilized to explain natural phenomena, to make sense of what is puzzling or disturbing" (Engel, 1977, p. 130), the belief system utilized by health professionals needs to be expanded to a more holistic perspective, which focuses on the person in his or her environment and which simultaneously incorporates patients' and their caregivers' illness experiences.

Engel's (1977) proposal of a biopsychosocial model, which offers a more holistic perspective, is now making headway in primary care, and the distinctions made between the different languages used by health professionals and lay people when talking about nonhealth have been investigated by social scientists, such as Berger (1991), Helman (1987; 1990; 1991), Kleinman (1980; 1986; 1987; 1988a; 1988b), Rogers (1992), and Rosenman (1978). However, early studies concerning the psychosocial factors in illness have

focused on the patient whose distress was both more visible and more accessible to research inquiry.

Thus, studies of the reactions of patients to such illnesses as cancer and heart disease were the first to emerge from a psychosocial perspective. [It is noteworthy that illnesses characterized by cognitive and affective disturbances, such as mental illness, stroke, and Alzheimer's disease, have had little parallel inquiry into patient distress]. (Biegel, Sales & Schulz, 1991, p. 24)

The few studies which have investigated psychosocial response patterns to impairment following brain injury (Lezak, 1978, 1986;

Prigatano, 1986; Romano, 1974; Sbordone, Kral, Gerard & Katz, 1984), provide implicit support for the importance of illness language by focusing on family members' reactions to the characterological alterations of brain injured patients.

However, these studies simultaneously reduce the significance of illness language by re-interpreting it in another framework (such as psychodynamic theory). For instance, Romano (1974) observed the responses of the families of 13 patients who had experienced traumatic head injury and found that family members not only reacted to the patient's injury with the initial understandable and expected denial, but that this denial persisted. She interprets the evidence of marked anger in family members' responses as being used in the service of maintaining their denial. Thus, family members' complaints that staff were maliciously withholding positive information from them is considered by Romano to be evidence of denial (Romano, 1974, p. 5).

The intention is not to invalidate Romano's interpretation, but to provide an example of how the generalization of family members' responses as evidence of denial masks the different experiences, meanings and cultural orientations of these members and therefore serves to negate their experiences. Their anger towards hospital staff may in fact be a function of this disqualification. Therefore, rather than translating illness

language into another language, it is important to analyse the way people talk and the nature of illness language, because this would validate patients' and caregivers' 'realities', and thereby create opportunities for more effective support and care of those faced with illness.

Mauss-Clum and Ryan (1981) investigated the responses of wives and mothers to their family member's head injury due to trauma, a vascular accident or Alzheimer's disease (AD), and also found that families strongly objected to early pessimistic predictions by health professionals. On the basis of this observation they conclude that hope is an important support during the immediate crisis. In addition, they found that family members ranked their need for a clear and kind explanation of the patient's condition as first priority, but only half of the family members who were interviewed reported receiving an explanation of the patient's condition, while 20 percent denied receiving any information and counselling. I would thus argue that in view of both the negation of family members' experiences by health professionals and staff (perpetuated by researchers' generalizations), and the tendency of professionals to not provide clear explanations of their perspectives on the patient's condition, it is understandable that family members' would react angrily toward hospital staff members. Describing their angry responses as evidence of denial not only negates family members'

experiences, but also implies that professionals can do little to be heard and understood by family members and vice versa. In contrast, describing their anger as a response to disqualification implies that it is possible for professionals and family members to understand each other and implement effective treatment and coping strategies.

Studies investigating the psychosocial aspects of stroke and Alzheimer's disease (AD) have recently begun to emerge, but most have focused on the burdensome nature of caregiving (Gilleard, Boyde & Watt, 1982; Gwyther & George, 1986; Zarit, Reever & Bach-Peterson, 1980; Zarit, Todd & Zarit, 1986), whereas others have attempted to identify variables involved in the prediction of depressive symptoms in caregiving. For example, Boss, Caron, Horbal and Mortimer (1990) examined the role of two perceptual variables - boundary ambiguity and mastery - in predicting the development of depression in caregivers of AD, and concluded that the more a caregiver perceives a mate as psychologically absent, the less masterful and the more depressed she or he is. Although these two perceptual variables may play a role in predicting the development of depressive symptoms in some caregivers of cognitively impaired patients, one should be cautious in generalizing this finding to all such caregivers since to do so implies that they construct and react to the problem in highly similar fashion. Rather, it is proposed that the caregiving of

chronic illness is a more complex process, with each caregiving experience being unique, and which cannot be fully understood by identifying specific variables through quantitative analysis. Consequently, techniques for the qualitative analysis of caregivers' language would appear essential in enabling health professionals to gain a more holistic perspective on the caregiving experience. Following Good and Good (1980), it is therefore argued that

the most critical and problematic variables seem to be the meaning a symptom has for the patient (and caregiver) and the idiom or language in which distress is experienced and communicated. (p. 173)

This argument is convergent with that of social constructionist approaches to family therapy, which view the reality of a problem - be it one of disease or purely behavioural in nature - as linguistically shaped by those interacting around it, including the therapist (Anderson & Goolishian, 1988; Butchart, 1988; Griffith, Griffith & Slovik, 1990). As a consequence of this emphasis on language, the vocabulary of family therapy has largely jettisoned cybernetic-systems metaphors in favour of a postmodern, anthropological metaphor - that of narrative (Hoffman, 1990). In anthropology, cultural constructivists are concerned with human experience and how local cultural history,

context and knowledge construct and shape it (Jenkins, 1991; Kleinman, 1988b). Similarly, the core of Kleinman's (1988b) argument is that illness has meaning and that to understand how illness obtains meaning involves the interpretation of illness narratives. Kleinman's (1988b) argument that the interpretation of illness narratives is an important task in doctoring, is taken a step further by Anderson and Goolishian (1988) who believe that

therapy is a process of expanding and saying the 'unsaid' - the development, through dialogue, of new themes and narratives, and, actually, the creation of new histories ... This resource for change, the not-yet-said, is not 'in' the unconscious or any other psychic structure. This resource is not 'in' the cell or the biological structure, nor is it 'in' a social structure such as the family. This resource is in the 'circle of the unexpressed'. This resource, this capacity for change, is in the ability we have 'to be in language' with each other and, in language, always to develop new themes, new narratives, and new stories. (p. 381)

The co-construction and analysis of illness narratives thus facilitates an understanding of patients' illness meanings, reveals the way cultural values and relations shape these

meanings, creates a context for new narratives and meanings to emerge, and enables professionals to discover "that aspect of the healer's art that is most ancient, most powerful, and most existentially rewarding" (Kleinman, 1988b, preface).

Accordingly, the interpretive framework for this study is provided by Kleinman's (1988b) work on the illness experiences of those faced with chronic illness. By engaging in meaning-generating discourse with caregivers whose spouses have had a stroke or suffer from AD, it aims to investigate their illness experiences so that a more detailed picture of the complex caregiving process may be obtained. Following a review of the literature on stroke and AD, it presents a conceptual investigation of the nature of the relationship between health professionals, patients and caregivers (particularly the languages of health professionals and caregivers), and a qualitative analysis of the illness narratives produced by seven caregivers, each of whom was interviewed twice with an interval of approximately one year between each interview. Discussion of these narratives demonstrates the diversity of culturally constructed realities that develop in different professional-patient interactions, and the final chapter examines the implications of this approach for future research and the care of stroke and AD sufferers.

CHAPTER 2

EPIDEMIOLOGY, ETIOLOGY AND BIOMEDICAL DESCRIPTIONS OF STROKE

Stroke: "a clinical syndrome (a collection of symptoms and signs) which has been defined ... as rapidly developed clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin ... Put more simply, it is the outward manifestation of a localized sudden interruption of the blood supply to some part of the brain." (Wade, Langton Hewer, Skilbeck & David, 1985, p. 6)

Stroke is the third leading cause of death in the United States after heart disease and cancer (Caplan & Stein, 1986). Stroke incidence - the number of new cases occurring in a given population over a set period - has been the subject of many studies, most of which agree that Western countries all have annualised incidence rates of between 150 and 250 per 100 000 population (Wade et al., 1985). On the other hand, stroke prevalence - the number of people who have ever suffered

a stroke and who are still alive on a particular day - has been less well studied. In most reports, prevalence is estimated from known incidence and survival data rather than directly measured (Wade et al., 1985). For example, a National Survey of Stroke in the USA suggested a prevalence of 794 per 100 000 on 1 July 1976.

In South Africa, the South African Medical Research Council's (SAMRC, 1987) review of South African mortality indicated that in 1984 there was a total of 35 074 recorded deaths due to diseases of the circulatory system. This accounted for 20,5 percent of all deaths and of those, 34,9 percent involved cerebrovascular disease. However, incidence and prevalence rates of stroke are not available in South Africa, and therefore a comparison with rates in the USA is not possible. Nevertheless, the SAMRC found that white and Asian males are at substantially higher risk than black and coloured males for death due to diseases of the circulatory system. White females are at less risk than Asian females for death due to circulatory disease, but at greater risk than coloured and black females. This pattern - white and Asian males and females at greater risk of death due to circulatory disease than black and coloured males and females - could be due to differences in lifestyles and eating habits, and is likely to change as industrialisation proceeds. With the move toward greater industrialisation in

South Africa, the incidence of stroke is likely to increase and mirror the incidence figures of other industrialized countries, such as the USA, putting more pressure on the health system to provide care (Yach & Von Schirnding, 1993).

What is a Stroke?

'Stroke' is the term commonly used to refer to the most frequently encountered of the cerebrovascular diseases - the cerebrovascular accident (CVA). This syndrome, involving neurological deficit of relatively rapid onset, is produced by one of several conditions that impair circulation of blood to the brain or spinal cord. Depending on the brain areas involved, there are a wide variety of symptoms affecting motor, sensory, cognitive, language and other functions.

Etiology of Strokes

According to Caplan and Stein (1986), there are two major mechanisms of brain damage in stroke patients: ischemia and hemorrhage. Detailed pathophysiological explanations of ischemic and hemorrhagic strokes are common in the literature on stroke (Barnett, 1986; Wade et al., 1985), but despite the fact that neuropsychological deficits are amongst the most frequent

sequelae (Walsh, 1985), relatively little attention has been given to their description. Accordingly, the following descriptions and explanations of the pathophysiological and neuropsychological aspects of ischemic and hemorrhagic strokes are largely derived from Lezak (1983).

Ischaemia. Ischemia is a pathological process whereby healthy brain tissue is deprived of essential nutrients, primarily glucose and oxygen, due to a lack of blood flow. The disruption of normal blood flow (infarction) creates an area of damaged or dead tissue (infarct). Caplan and Stein (1986) subdivide ischemic strokes into those that follow from different mechanisms, such as thrombosis and embolism.

Thrombotic strokes occur when there is an obstruction of blood flow due to the narrowing or occlusion of a blood vessel by clumps of blood particles and tissue overgrowth (a thrombus), which accumulate in arteriosclerotic plaques and build up within the artery walls. Arteriosclerotic plaques are the most common source of thrombotic obstructions, affecting mainly the larger extracranial and intracranial vessels. Growth of the thrombus narrows the lumen (opening) of the blood vessel and thereby reduces blood flow or closes off the vessel altogether. Thrombotic strokes may occur suddenly, but are usually preceded by transient ischemic attacks - "little strokes" - which last

less than 24 hours by definition (Lezak, 1983).

An embolic stroke occurs when a plug of thrombic material (an embolus) formed elsewhere within the vascular system breaks off and lodges in a vessel, thereby blocking the blood flow. Most emboli are fragments of thrombotic lesions that developed outside the intracranial circulatory system; mainly in the heart and blood vessels. Unlike thrombotic strokes, embolic strokes occur more suddenly and without warning.

The effects of ischemic infarctions vary from patient to patient depending on a number of different factors, such as individual differences in the anatomical organization of the cerebral circulation, and variations in the extent, sites and severity of arteriosclerotic disease. Age and sex may also play a role in determining the presentation of a stroke (Eslinger & Damasio, 1981). For example, embolic strokes tend to occur at an earlier age than thrombotic strokes and are more likely to involve anterior areas of the brain (Lezak, 1983). Consequently, each stroke is an individual event.

Nevertheless, certain overall patterns in onset and manifestations can be identified. Strokes generally tend to have one-sided effects, lateralizing to the right or to the left. During the acute stages, secondary effects of the stroke, such as edema (swelling), can cause more serious bilateral or diffuse

damage than the stroke itself and may result in death. Thus, during the acute stages of the illness, patients often display signs of bilateral or diffuse damage, which may diminish and dissipate altogether as swelling decreases and other physiological disturbances return to a more normal state. After the initial acute stages of the illness, most patients who experienced ischemic strokes are left with some lateralized deficits and relatively minimal evidence of diffuse damage. Their focal deficits typically fit into a pattern of dysfunction associated with areas of the brain that share a common artery or network of smaller arterial vessels (Lezak, 1983).

Hemorrhage. Hemorrhagic strokes occur when blood is released into the extravascular space within the cranium, thereby increasing the pressure within it. This increase in pressure cuts off connected pathways, which in turn causes localized or generalized injury to brain tissue. Caplan and Stein (1986) further divide hemorrhagic strokes into two subtypes - subarachnoid and intracerebral. In the subarachnoid hemorrhage, bleeding usually originates from aneurysms - "weak vessel wall(s) that can balloon out and ultimately burst under pressure" (Lezak, 1983, p. 178) - or arteriovenous malformations. Blood leaks out of the vascular bed on the brain's surface and spreads into the spaces around the brain by means of the spinal fluid pathways.

Bleeding due to a ruptured aneurysm is usually faster and at a greater pressure than bleeding due to other causes, such as trauma and suddenly increasing intracranial pressure. The patient may or may not lose consciousness, depending on the severity of the bleed, but the condition can be fatal when massive bleeding occurs. However, if the bleeding is arrested soon enough, relatively little brain damage may result.

In those cases where the damage is extensive but not fatal, patients tend to display behavioural impairments attributable to focal damage (Lezak, 1983). However, the neuropsychological deficits resulting from ischemic strokes are likely to be more widespread than those resulting from ruptured aneurysms, because when an aneurysm ruptures the flow of blood into the extravascular space within the skull is liable to affect a larger area of the brain than the more localized blockage of a blood vessel due to ischemic infarctions. Warning signs rarely precede these hemorrhagic strokes. The manifestations of ruptured aneurysms range from painful headaches, often accompanied by nausea, to severe neurological dysfunction and even death.

Strokes due to intracerebral hemorrhage most often occur in conjunction with hypertension (high blood pressure). Unlike the type of bleeding which occurs in subarachnoid hemorrhages, the blood flows directly into the brain substance and the degree of

damage depends on the location, rapidity, volume, and pressure of the bleeding (Caplan & Stein, 1986). The area usually affected by intracerebral hemorrhages is the subcortical area of the cortex (the thalamus, basal ganglia and brain stem). Consequently, these intracerebral hemorrhages have a mortality rate of around 50 percent, and the condition of those who survive such strokes can vary from near-vegetative to relatively good return to independence. Neuropsychological deficits evident amongst those who show improvement include attention and memory problems, irritability, and some subtle changes in psychosocial and self-regulatory behaviour, typically associated with frontal lobe lesions (Walton, 1977).

The description of these five major subtypes of stroke is important, because it reflects the heterogenous nature of strokes and facilitates accurate diagnosis and effective medical treatment. The problems presented by these major subtypes of stroke are quite distinct and require different treatment strategies (Caplan & Stein, 1986). For example, in subarachnoid hemorrhage, treatment is aimed at preventing the next aneurysmal leak, whereas in intracerebral hemorrhage rebleeding is rare and treatment is aimed at controlling local bleeding and pressure.

Since modern treatment approaches are constantly improving, stroke mortality rates have been declining steadily in recent

years in the United States as well as in other industrialized nations (Garraway, Whisnant & Drury, 1983). The implication of this decline is that a higher order problem has evolved: there is an increase in the number of disabled stroke survivors and caregivers - all requiring support and assistance.

In South Africa, the Stroke Aid Society was formed in response to the need for support of stroke victims and their caregivers. However, is it reasonable to expect this society to be solely responsible for responding to the needs of the caregiver? What role do medical practitioners and clinical psychologists, in particular, play at present in providing support to both patients and caregivers and how could their contribution be improved? This study aims to address these issues.

CHAPTER 3

EPIDEMIOLOGY, ETIOLOGY AND BIOMEDICAL DESCRIPTIONS OF ALZHEIMER'S DISEASE

Alzheimer's disease: "a progressive reduction in the ability to think, remember, learn and reason, leading to a reduced capacity for self-care and self-direction." (Woods, 1989, p. 7)

Alzheimer's disease (AD) is the most common of a family of debilitating, dreaded conditions known collectively as the 'dementias'. There are various interpretations of the term 'dementia' and here the term is understood to refer to the "global deterioration of mental functions due to organic diseases of the cerebral hemispheres ... which have a chronic and irreversible course" (Golper & Binder, 1981, in Lezak, 1983, p. 180). Thus, all of the degenerative disorders in which there is progressive deterioration of brain tissue qualify as 'dementias', with AIDS perhaps being the most prominent of the degenerative disorders at present.

Alzheimer's disease has a profound impact on all who suffer from it, as it insidiously deprives individuals of their unique thought processes, their insights, judgement and their ability

to learn new information. In its Diagnostic and Statistical Manual of Mental Disorders (APA, 1987, p. 107), the American Psychiatric Association identifies the following clinical symptoms as evidence of dementia: impairment in short-term memory (inability to learn new information) and long-term memory (inability to remember information that was known in the past), and evidence of at least one of the following symptoms - impairment in abstract thinking; impaired judgement; disturbances of higher cortical function, such as aphasia (disorders of language), apraxia (inability to execute motor functions despite intact comprehension and motor function), agnosia (failure to recognise or identify objects despite intact sensory function), constructional difficulty (such as the inability to copy three-dimensional figures), and personality change (in other words an alteration or accentuation of premorbid traits).

Epidemiology

Alzheimer's disease affects more than 2,5 million Americans and is the fourth leading cause of death in the USA, causing 150,000 deaths annually (Rosin, 1987). In the UK it is estimated that 750,000 people suffer from AD and its related conditions (Woods, 1989). In South Africa, incidence and prevalence rates of Alzheimer's disease are not available, and

therefore such studies should be conducted in the future.

Jorm, Korten and Henderson (1987) have provided a quantitative integration of the literature on the prevalence of dementia in Japan, Russia, Scandinavia, Britain and the USA. Their analysis of dementia prevalence studies showed no overall sex differences, but when studies of specific dementing diseases (such as AD) were analyzed they found that prevalence rates for AD tended to be higher among women than men in these countries (Birkett, 1972; Nishihara & Ishii, 1986). This may be because women tend to live longer than men and therefore are more prone to die with any age-related disease. However, unlike prevalence studies, incidence studies concerning sex differences in AD yield rather inconsistent results. Some studies show a higher incidence of AD amongst women (Åkesson, 1969; Mölsä, Marttila & Rinne, 1982) while others show no difference in incidence rates of AD amongst men and women (Schoenberg, Kokmen & Okazaki, 1987). According to Jorm (1990), these inconsistencies are perhaps related to differences in case ascertainment procedures, and the more consistent sex differences found in prevalence studies may reflect survival differences. In other words, there may be no sex differences regarding the incidence of AD, but women with AD may survive longer than men affected by this illness, resulting in higher prevalence rates of AD in women than in men.

If one accepts the general finding of higher prevalence rates of AD amongst women than men, one may be tempted to assume that more husbands than wives are caregivers. However, because women tend to live longer than men, it is more likely that women with AD are cared for by their children or by staff in homes for the aged, whereas men with AD are more likely to be cared for by their wives.

Phases of Alzheimer's Disease

Reisberg (1981) has divided the progression of AD into five phases. Knowledge of these stages helps determine the rate at which the illness is developing and facilitates the identification of symptoms and the tracking of their progression as the illness develops.

Stage 1: Early Confusional Phase. During the initial stages of AD, the patient may seem merely forgetful, and may also start finding it difficult to deal with sudden changes in her environment. Finding the right words to communicate becomes a problem and difficulty recalling recent events is evident. The AD patient will also begin to lose her spontaneity and sparkle and is often easily upset as a result of the uncertainties created by memory problems.

Stage 2: Late Confusional Phase. During this stage, memory problems become more evident and pervasive. The AD patient's orientation to time, place and person may still be intact and memories of the distant past appear unaffected. However, as patients see their capabilities disappearing, they are likely to become more focused on themselves and insensitive to the feelings of others. At this stage the AD sufferer may still be denying she has problems and may see any assistance as interference.

Stage 3: Early Dementia. At this point in the course of the illness, the patient has become quite dependent on others for her care, her memory deteriorates further, and a heightened sense of insecurity can develop into suspicion and paranoia. This may be accompanied by anger when others attempt to disprove her accusations as unfounded, and agitated behaviour may develop. Alzheimer's victims can be expected to withdraw from social and task-oriented activities during this stage.

Stage 4: Middle Dementia. As AD progresses from early to middle dementia, major changes occur and the involvement of caregivers increases. Delusions reflecting fear of loss and imagined threats in the external world are prominent and the patient's sleep is often disrupted and erratic. Impulsive symptoms may also develop during this stage, and help with daily activities is essential. A fear of bathing and lack of awareness

of their surroundings also characterize the behaviour of sufferers during this phase of the disease. The emotional burdens of caregiving start to take their toll at this point and caregivers may consider placing the patient in an institution, while simultaneously making greater use of support groups, where these exist.

Stage 5: Late Dementia. During the final phase of AD, treatment decisions have to be made without the approval of the sufferer. Motor abilities continue to deteriorate and eventually the control of bladder and colon functions is lost. The ability to chew and swallow food is affected and as brain activity becomes disturbed, the patient is increasingly vulnerable to seizures, pneumonia, infection and other illnesses. Stupor occurs in the terminal stages and leads finally to coma and death.

Etiology

Since 1907 when Alois Alzheimer, a German neurologist, described the changes in the brain of a 51-year old woman who died after a four and a half year loss of ability, research into AD has produced several schools of thought about possible causes.

Recent studies concerning the causative and contributing factors in the development of AD suggest that people who have sustained head trauma may be at greater risk for AD (Clinton, Ambler & Roberts, 1991; Mortimer, French, Hutton & Schuman 1985; Mortimer et al, 1991). Thus, in South Africa where the annual incidence of traumatic brain injury (TBI) in Johannesburg was found by Nell and Brown (1991) to be considerably higher than the annual incidence of TBI in the United States (316 and 200 per 100 000 population respectively), one might expect incidence and prevalence rates of AD to be higher than those in the USA. If this is the case, both TBI and AD could be described as 'silent epidemics' in South Africa. However, further research is necessary to determine the extent to which prior head trauma plays a role in the development of AD.

Until recently, a positive diagnosis of AD could only be established post-mortem when senile plaques containing a central core consisting of amyloid surrounded by abnormal neurites were found on autopsy. Although senile plaques have also been observed in the brains of the elderly in general, there is a significantly greater number of these plaques in the brain of the AD sufferer. However, the introduction of computerized axial tomography (CAT), positron emission topography (PET) and electroencephalograph (EEG) scans have now made it possible to

establish the extent of brain atrophy in the living, a prominent feature in AD and the other dementias.

Although technological progress has facilitated the diagnosis of AD in the living, accurate diagnosis is still difficult because scans are not sensitive enough to detect evidence of brain atrophy during the initial stages of a dementing process and there is a lack of diagnostic criteria to discriminate AD from other dementing disorders. However, psychological testing has aided the diagnosis of AD, and a number of instruments have been devised to provide global measures of personal and social functioning. For example, Cummings and Benson (1986) have devised the DAT (Dementia of the Alzheimer Type) Inventory in order to improve diagnostic accuracy and identify operational criteria to distinguish it from other dementias.

Nevertheless, at this time there is no definitive medical or psychological test that can diagnose AD. Therefore, other potential causes of dementia, such as toxic conditions, infections, nutritional and endocrine disorders, slow-growing tumours, depression and metabolic disturbances need to be ruled out before a diagnosis of AD can be made. Unlike AD which is irreversible and progressive, many dementias due to the above conditions can be reversed if identified and given early

treatment. Thus, although the causes of some dementias can be determined, the etiology of AD remains uncertain, as reflected in the diversity of theories that attempt to explain it.

Viral theory. This theory holds that AD is caused by a slow, infectious virus that may take several decades to incubate. In order to prove that such a virus for AD exists, clinical studies would have to show that the disease can be transmitted, but thus far attempts to transmit the disease from brain tissue to animals have failed. This failure could be due to the animals not being susceptible to the disease or because the incubation period for the disease is longer than the duration of the studies (Prusiner, 1984). Thus, although other neurological disorders (such as Creutzfeldt-Jakob disease) have been found to be caused by such viruses, there is no evidence of a viral cause in AD at present.

Immune-system theory. Research has found that the number of autoimmune antibodies in the blood increases with age and that the elderly tend to get more autoimmune diseases, such as cancer and late-onset diabetes (Nandy, 1983). Consequently, such age-related factors suggest that deterioration of the immune system may also be implicated in AD. Another possible cause is a disorder in the body's immune system, causing the body to attack itself, while other indicators suggest non age-related immune

system abnormalities. For example, other neurological diseases, such as multiple sclerosis and AIDS, are known to involve immune-system alterations and several studies report findings of marked immune-system irregularities in Alzheimer's patients (Gruetzner, 1988). However, far more research is needed to fully evaluate this theory.

Aluminium theory. The concentration of aluminium in the human brain is known to increase with age (Jenike, 1985), and abnormally high levels of aluminium have been found in the brains of persons suffering from other dementias, although these may be unrelated to the disease. These indications suggest that high levels of aluminium may possibly be related to AD, but there is no proof of it being a causative factor.

Genetic theory. Research has determined that genetic factors do play a role in AD, but thus far AD has not been widely shown to correspond to known patterns of inheritance. Jorm (1990) points out that although it seems there may be some genetic predisposition toward AD, both a genetic factor and other factors must be involved in the development of the disease. The part played by genetic factors in other disorders, such as Down's syndrome, which shares several features in common with AD, has been investigated. However, although there appears to be a

possible genetic link to AD, further genetic research needs to be conducted.

Ageing and environment interaction theory. Calne, Eisen, McGeer and Spencer (1986) have proposed that environmental exposures (including trauma, toxins and infectious agents) can cause loss of neurones in specific areas of the central nervous system which do not have clinically significant effects at the time, but compound with the normal loss of neurones which occurs with ageing to produce neurological disorders, such as Parkinson's disease and AD, in later life. This theory does not specify a single environmental cause for the initial neuronal loss, but allows for multiple possibilities. More research is therefore needed to investigate the extent to which these various factors contribute to the development of AD. However, even once the role played by these factors is clarified, this theory is limited, because genetically-mediated effects are not considered.

The five theories of AD presented here are not mutually exclusive. Several of the mechanisms they postulate could operate simultaneously and it is not difficult to sketch an overarching theory incorporating elements of them all. However, the broad overarching theory sketched by Jorm (1990) is "unfortunately rather jelly-like in its ability to be moulded to fit any new fact" (Jorm, 1990, p. 170).

This brief discussion of the etiology of AD reveals that considerable research needs to be conducted regarding its etiology and development, with a view to its prevention. The financial implications of such extensive, thorough research are obvious. In fact, the amount of money spent on research has been minute when one compares it with the costs of community support services, hospital treatment, and residential provision of care (Woods, 1989). In Canada, with around 300,000 sufferers, it is estimated that the cost runs up to 1,5 billion dollars and in the USA, with around 2,5 million sufferers the expenditure is more than 50 billion dollars (Woods, 1989). In South Africa, where problems such as tuberculosis and high infant mortality - created by Apartheid's legacy of selective impoverishment - are prominent, Alzheimer's disease constitutes a problem of relatively minor importance. Consequently, less time and funds are allocated to the care of the Alzheimer patient. Thus, family members are usually the only source of care and support for these sufferers, and consequently have a difficult, painful task to carry out alone.

The aim of this review has been to provide a broad overview of the disease as an object of biomedical knowledge. From this it is apparent that while the origins of AD remain somewhat of

a mystery to researchers, medical professionals could nevertheless provide caregivers with information about AD and thereby prepare the families of AD patients for the future.

CHAPTER 4

LANGUAGE, TIME, CULTURE: THE ILLNESS-DISEASE DICHOTOMY

Language

The central role played by language in constructing and communicating social and individual reality is acknowledged by various authors, such as Good and Good (1980), and Gadamer (1976):

There is no societal reality, with all its concrete forces, that does not bring itself to representation in a consciousness that is linguistically articulated. Reality does not happen "behind the back" of language; it happens rather behind the backs of those who live in the subjective opinion that they have understood "the world" ... ; that is, reality happens precisely within language. (Gadamer, 1976, p. 35)

From this perspective, the preceding chapters on the epidemiology and etiology of stroke and Alzheimer's disease not only clarify the nature, course and possible causes of these chronic illnesses, but also exemplify the dominant language of disease inherent in the literature. Highly technical medical terminology - such as diagnosis, etiology, ischemia, thrombosis, aphasia,

apraxia and agnosia - is central to this language of biomedicine, the chief purpose of such terms being to aid the medical practitioner in identifying the disease causing the symptoms so that once a diagnosis is made, treatment can be implemented.

However, this world of lesions, apraxias and agnosias is a world of clinical certainty and concrete precision distant from the uncertain world of irritability, emotional ambiguity and confusion inhabited by caregivers and patients. It is in an attempt to clarify the quality of these different worlds that Kleinman (1988b) distinguishes between 'disease' and 'illness'; the former being the object created by biomedical terminology toward which treatment is directed, and the latter the experience of patients and caregivers.

By invoking the term illness, I mean to conjure up the innately human experience of symptoms and suffering. Illness refers to how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability.

(Kleinman, 1988b, p. 3)

Flowing from this are the additional categories of 'illness behaviour', 'illness complaints', 'illness problems' and 'illness experience' (Kleinman, 1988b). Illness behaviour refers to the patient's initiation of treatment (for example, changing

diet and activities) or the decision to seek care from health professionals. Once patients and their families decide to seek care from professionals, illness complaints are shared with them. These complaints could include both the presentation of symptoms that the patient is experiencing (such as difficulty in focusing on one's work due to headaches, which may lead to feelings of frustration and anxiety) and the description of illness problems (the principal difficulties that symptoms and disability create in our lives). Thus, 'illness experience' designates the categorization and explanation of symptoms causing distress in common-sense ways accessible to those who comprise the social group to which the patient belongs.

However, because the language of disease constructs objects rather than experience, it devalues the significance of such meaning, and the illness complaints of the patient are translated into signs of disease - "diagnosis is a thoroughly semiotic activity: an analysis of one symbol system followed by its translation into another" (Kleinman, 1988b, p. 16). This other symbolic system - the language of disease - is therefore created by the clinician. Although locally shared idioms - such as 'stress' - may initially create a common ground for the patient and clinician to understand each other, these can rapidly become a barrier to further understanding, as in the following example

of Cynthia P., the wife of an AD patient. On consulting a neurologist about her husband's condition, the neurologist said, "No, there is nothing. I don't see anything, he is just deeply stressed about the son and that's that". This deduction made by the neurosurgeon exemplifies Kleinman's (1988b) statement that "clinicians sleuth for pathognomonic signs - the observable, telltale clues to secret pathology - that establish a specific disease" (Kleinman, 1988b, p. 16). When they do not find these signs in the shape of tangible evidence for disease, their explanatory models break down and they fall back upon vague constructs, such as 'stress', to explain the problem. Cynthia was dissatisfied with this attribution of her husband's behaviour to the stress consequent on their son's "drug-induced schizophrenia", because based on a number of incidents she had experienced with her husband over a period of time, she believed that he was ill and not merely suffering from stress:

I remember we went to Cape Town for some reason again. We went into the synagogue, we came out and I saw he had left the car door open. The next night we went somewhere for supper. When we got out the car wouldn't start; he had left the car lights on. That in itself is not so terrible if (all of us do it), but he was doing it often. Like I'd notice (he was a very

astute and very good businessman; he looked after his business and his clients extremely well) and I'd notice that he would forget to do a job. Somebody would phone and say, "Where are you, you were coming to give me a quote" or "What happened? My job was -" And then I had, then started the three or four most horrible years of my life, because I could see he was forgetting everything. (First interview, 8 July 1992)

These experiences were not elicited by the neurologist, and as Kleinman (1988b) points out, clinicians may even construe such illness experiences as obscuring the traces of morbid physiological change, whereas for the caregiver of the chronically ill it is the very stuff of care; "a symbol that stands for itself" (Wagner, 1986, in Kleinman, 1988b, p. 17). Should the clinician's explanation of the illness (the diagnosis) and the treatment thereof fit with the patient's understanding, the patient may incorporate the clinician's explanations into his belief system. However, if the clinician's diagnosis does not fit with the patient's belief system, a situation develops where the patient becomes a problem patient, who in turn reciprocally experiences care as a problem in the health care system. Thus,

the devaluation of meaning and the overvaluation of the technical quest for the control of symptoms, "is a serious failing of modern medicine: it disables the healer and disempowers the chronically ill" (Kleinman, 1988b, p. 9).

Meaning and Narrative Discourse

In recent years, introduction into the social sciences of postmodern ideas originating from semiotics and literary criticism has led increasingly to thinking about social fields of study as if they were a narrative or a text (Hoffman, 1991). Consequently, a branch of textual interpretation - hermeneutics - has been revived by various social scientists (Anderson & Goolishian, 1988; Good & Good, 1980). The hermeneutic approach to studying social reality posits that the process of translating across diverse sets of meanings is analagous to textual interpretation:

Interpretation, in the sense relevant to hermeneutics, is an attempt to make clear, to make sense of ... a text, or a text analogue, which in some ways is confused, incomplete, cloudy, seemingly contradictory - in one way or another unclear. The interpretation aims to bring to light an underlying coherence or sense. This means that any science which can be

called 'hermeneutical' even in an extended sense, must be dealing with one or another of the confusingly interrelated forms of meaning. (Rabinow & Sullivan, 1979, p. 25)

Family therapists who adopt a hermeneutic approach, such as Anderson and Goolishian (1988), replace the feedback loops of cybernetic systems with the intersubjective loops of dialogue. Analysis of Anderson and Goolishian's (1988) work and the ideas of social constructionists (Gergen, 1985) reveals the manner in which many adherents of postmodernism are dismantling the philosophical foundations of Western thought. Rather than taking either the idealist position (the view that knowledge derives from internal constructs) or the positivist position (the view that knowledge is a representation of facts and events in a 'real' world), social constructionists believe that all knowledge evolves in the space between people:

Social constructionism views discourse about the world not as a reflection or map of the world, but as an artifact of communal interchange. (Gergen, 1985, p. 266)

Gergen (1985) argues that self-narratives are socially produced and are neither reflections of 'reality' nor representations of the person's 'true' personality traits, beliefs and behaviour.

Therefore, based on the social constructionist idea that self-narratives are socially produced, the illness language of caregivers' narratives suggests a complex of ideas and actions generated in interactions with others. Thus, the evolving set of meanings which emerge from these interactions are not skull-bound and do not exist inside what we think of as an individual 'mind', but are part of a general flow of constantly changing narratives (Hoffman, 1990).

In Chapter One, it was pointed out that within the field of family therapy there has been a departure from cybernetic-systems metaphors, which compare a family to an organism or machine (Bateson, 1971; Maturana & Varela, 1980, 1987). Due to this departure, hydraulic metaphors like 'homeostasis' (Jackson, 1957), which are used to explain how entities remain the same, and machine terms like 'cybernetics' (Bateson, 1971), 'structural coupling' (Maturana & Varela, 1980) and 'autopoiesis' (Maturana & Varela, 1980), have been replaced by linguistic constructs like 'text', 'narrative' and 'history'. These linguistic terms are more appropriate than biological and machine metaphors because, firstly, therapy is an art of conversation (and therefore terms like "text" and "narrative" are "closer to home"), and secondly, terms like "history" and "narrative" imply that entities are always in the process of change (Hoffman, 1990). Furthermore, because these terms are accessible in that their meanings are

self-evident, they can be utilized by health professionals from various disciplines in different contexts, thereby enabling establishment of a common language between these professionals.

According to Kleinman (1988b), the illness narrative - "a story the patient tells and significant others retell, to give coherence to the distinctive events and long-term course of suffering" (Kleinman, 1988b, p. 49) - informs health professionals about how life problems are created, controlled and made meaningful, and contributes to the experience of symptoms and suffering by shaping the experience further, such that new experiences evolve during the narrative process. The interpretation of illness narratives in the light of different modes of illness meanings is imperative, because in the course of chronic illness patients, caregivers and health professionals become increasingly aware that these meanings can amplify or dampen symptoms, exaggerate or lessen disability and impede or facilitate treatment (Kleinman, 1988b).

Illness meanings. Kleinman (1988b) delineates four different modes of illness meaning - symptom, cultural significance, life world, explanation and emotion - which can be identified in patients' and caregivers' illness narratives. Symptom as meaning refers to the conventional signification of the symptom. For example, palpitations signify distress and

paralysis might mean that a person has suffered a stroke. The meanings of symptoms are standardized 'truths' in a local cultural system in that the categories a group fabricates are then projected onto the world and called natural, because they are 'found' there. The second mode of illness meaning - cultural significance - refers to the fact that certain symptoms and disorders bring particularly powerful cultural significance with them, often of a stigmatizing kind. Cultural meanings related to certain illnesses, such as AIDS, brand the sick person with a significance which is often neither easily warded off nor coped with by the patient. Consequently, these meanings present problems to the patient, caregivers and health professionals which are as difficult as the disease itself.

In the context of chronic illness, the illness absorbs personal, interpersonal and social significance from the patient's life world. These different meanings are integrated into daily living and influence the way in which the patient copes with the illness and how caregivers and significant others behave toward the patient.

During the course of the illness, patients, caregivers and health professionals also attempt to create acceptable explanations of the various aspects of the illness and its treatment. Thus, the patient and anyone in the social network,

the media, or the orthodox and alternative therapeutic systems, construct explanatory accounts in response to a number of different questions, such as - What does the illness do to my body? What course can I expect the illness to follow in the future? These explanatory models (EMs) - the conception about illness and treatment held by patients, caregivers and practitioners - vary in degree of sophistication, coherence, clarity and explanatory power. The influence of basic social and cultural determinants can be detected in how EMs may cluster according to class, education, occupation, etcetera. These determinants are also likely to influence how illness is defined, what personal and family meaning it has, what decisions are made regarding treatment, and how treatment is evaluated. Thus, the illness behaviour of patients and the behaviour of caregivers and health professionals are often a direct outgrowth of these beliefs (Manschreck & Kleinman, 1977). Health care relationships (e.g. patient-practitioner or caregiver-practitioner relationships) can be studied as transactions between different EMs, and evidence suggests that when professionals elicit, analyze and negotiate with patient and caregiver EMs, problems in clinical communication are reduced and care is facilitated (Lazare, 1974).

Thus, should the clinician wish to treat patients effectively, patients' illness experiences need to be legitimated by the clinician. In other words, the clinician needs to authorize that experience and "audit" it empathically (Kleinman, 1988b).

Time

As a second step in developing a framework by which to legitimate the reality of illness while simultaneously acknowledging that of disease, it is useful to consider Rolland's (1984) psychosocial typology of chronic illness. Instead of constructing diseases as objects, this typology characterizes them as dynamic processes distinguished from one another in terms of their impact upon social time and space. Rolland (1984) construes chronic illness in terms of four dimensions - onset, course, outcome and degree of incapacitation. Each of these dimensions are now discussed with reference to stroke and AD, because it is hypothesized that differences between these illnesses in terms of onset, course, outcome and degree of incapacitation are likely to influence the experiences of caregivers in different ways.

The Illness Dimensions

Onset. The first difference between stroke and AD pertains to the onset of these illnesses. Stroke has a sudden, acute onset, whereas AD develops gradually. Consequently, the gradual development of AD constitutes a different form of stressor to caregivers than the sudden occurrence of a stroke.

Although the total amount of readjustment to family structure, roles, problem solving and affective coping might be the same for both illnesses, the acute onset of stroke requires that these changes be executed more rapidly. Some families are able to mobilize crisis management skills more readily than others. Families faced with AD, on the other hand, have a more protracted period of adjustment, although the confusion experienced concerning the symptoms of AD can be a source of anxiety, conflict and despair.

Course. The course of chronic illness can take one of three forms - progressive, constant, or episodic. AD is a progressive disease of increasing severity. Thus, periods of relief from the demands of the illness are minimal and continual adaptation and role change is necessary. Stroke follows a constant course, because biological changes typically stabilize after the initial event, and the chronic phase is usually characterized by some clear cut deficit, such as paraplegia, speech loss or

cognitive impairment. Although recurrences may occur, caregivers are faced with a semi-permanent change that is stable over a considerable time span. As in the case of AD, the potential for family exhaustion exists in stroke cases, but without the constant need for role changes over time evident in families dealing with AD.

Outcome. A critical distinguishing feature is the extent to which chronic illness is a likely cause of death and the degree to which it can shorten one's life span. At the one extreme are illnesses, such as AIDS, which are in most cases progressive and fatal, while an intermediate and more unpredictable category includes illnesses which shorten the life span (such as AD), and those where there is the possibility of recurrence, such as stroke. Although all chronic illnesses potentially involve the loss of bodily control, one's identity, and intimate relationships, for a life-threatening illness the loss of control entails greater consequences - death and the permanent loss of relationships. For caregivers faced with the possible recurrence of stroke, the "it could happen" nature of the problem fosters an unpredictable context which may lead to caregivers being over-protective toward the patient. In the case of AD, the patient and family members are confronted with the knowledge that the patient will gradually become more dependent

and ultimately no longer able to communicate with or recognize family members. Unlike the undercurrent of anticipatory grief permeating the experiences of families affected by stroke, for those affected by AD the grieving process begins once the family members have accepted the diagnosis. In fact, an initial period of denial serves to protect those dealing with AD from accepting the imminent loss of the patient and from grieving for this loss. Therefore, families gradually become caught between a desire for intimacy and a pull to "let go" emotionally of the ill member.

Incapacitation. The fourth category of Rolland's (1984) psychosocial typology of chronic illness is incapacitation. This refers to the impact of illness upon the social space and mobility of the patient and caregivers. Incapacitation can result from the impairment of cognition (eg AD), sensation (eg blindness), movement (eg stroke with paralysis), energy production and disfigurement and other medical causes of social stigma. These different kinds of incapacitation imply sharp differences in the specific adjustments required of a family. In the case of stroke, incapacitation is often worse at the time of onset, magnifying family coping issues related to onset, expected course and outcome. In the case of AD, however, incapacitation is initially less evident and is merely anticipated in the initial stages of the illness, thereby allowing

the family more time to prepare both emotionally and practically for this anticipated incapacitation. Rolland (1988) points out that the net effect of incapacitation on a particular patient and his family depends on the interaction of the type of incapacitation with the pre-illness role demands of the ill member and the family's structure and flexibility.

The extent to which chronic illnesses are predictable was not formulated as a separate category in Rolland's (1984) typology, because he argues that it is a product of interaction between the different dimensions of illness and therefore unique to every case (Rolland, 1988, p. 152). The predictability of a chronic illness is shaped by two main factors (Rolland, 1988). Firstly, the actual nature of the onset, course, outcome or presence of incapacitation, of a chronic illness is uncertain. For example, the manifestation of a stroke will depend not only on the type of stroke, but also on a number of other factors such as the particular brain region affected by the stroke, age, sex and state of health of the patient. Therefore, although common patterns might be expected in certain types of strokes (whether they be thrombotic, embolic or hemorrhagic) other factors influence the nature of the onset, course and presence or absence of incapacitation, making each stroke an individual event. The unpredictable course and outcome of stroke can therefore

complicate long-term planning. Secondly, diseases can vary as to the rate at which changes occur. Although AD has a more predictable course and outcome than stroke, the rate of progression of AD varies in different cases. Long-term planning is thus possible, but a more gradual rate of development of the disease may require that caregivers have more stamina. However, a stepwise progression of AD may provide some periods of relief since there may be less need for continual adaptation and role changes.

Illness Time Phases

Each of the four illness dimensions correspond with a particular temporal phase of chronic disease. These time phases - crisis, chronic and terminal - aid in providing a context for the integration of various aspects of the assessment and encourage clinicians to think longitudinally and to understand chronic illness as an ongoing process. They also enable health professionals to assess a family's strengths and vulnerabilities in relation to the present and future phases of the illness. According to Rolland (1988), each time phase has its own psychosocial tasks which require significantly different strengths, attitudes or changes from a family and thus are an important consideration in this study, because spouses are

interviewed at different points in time in the course of AD and stroke. Consequently, their descriptions and explanations of their illness experiences are likely to be shaped by, and give shape to, the psychosocial demands upon them at the time of interview.

In her investigation of psychosocial response patterns to severe traumatic brain injury, Lezak (1986) acknowledges the importance of the time dimension by identifying six stages in the evolution of family reactions to a brain damaged person, while in Butchart's (1988) study of stresses within the contexts of brain damaged people findings were grouped according to their location in time relative to the trauma. In this study, the similarities and differences that AD and stroke caregivers are likely to experience will be analysed in accordance with Rolland's (1988) three major time phases: (a) crisis, (b) chronic, and (c) terminal.

Crisis phase. According to Rolland (1988), this phase includes both the symptomatic period before actual diagnosis when the patient and family have a sense something is wrong, and the initial period of readjustment and coping after the problem has been clarified through a diagnosis and initial treatment plan. The crisis phase and the way in which it is dealt with by family members will differ in the case of AD and stroke. The sudden

upheaval due to the occurrence of a stroke and the resulting shock experienced by the patient and his family is likely to have a greater impact than the gradual confusion and anxiety experienced by the AD patient and his family during the pre-diagnosis phase. After the diagnosis of AD, although the individual and his family may experience some relief that a diagnosis has finally been made, they will also probably experience shock followed by a phase of denial. The fact that physical impairment is not evident in the AD patient at this stage of the illness, unlike the stroke patient who is likely to manifest clear motor problems (such as hemiplegia), is probably what contributes to the denial evident in family members of AD patients.

Chronic phase. This phase is the short or long time span between the initial diagnosis and readjustment period and the third phase when issues of death and terminal illness predominate. This phase, also known as "the long haul" or "day-to-day living with chronic illness" phase (Rolland, 1988, p. 155), can be characterized by constancy, progression or episodic change. Those families coping with stroke can usually come to terms psychologically and organizationally with the permanent changes presented by the stroke during this phase, although those dealing with the aftermath of a massive stroke may have to cope with an exhausting problem "without end" (Rolland, 1988, p.155). Families which have to cope with the gradual incapacitation of

an AD patient also have to come to grips with a problem, which does not seem to end. Consequently, the possibility of resuming a 'normal' life, might only come through the death of their ill member.

Terminal phase. The final phase - the terminal period - includes the preterminal stage of an illness where the inevitability of death becomes apparent and increasingly predominates in family life, as well as the periods of mourning and resolution of loss. Issues pertaining to separation, death, grief, resolution of mourning and resumption of 'normal' family life beyond the loss, distinguish this phase from the crisis and chronic phases.

Culture

The aim of this chapter has been to acknowledge the central role played by language in constructing and communicating individual and social reality and to develop a framework by which the reality of illness and that of disease can be legitimated. Through this process two premises central to this study have been articulated. Firstly, illness is a transactional, communicative and social experience; it is not simply personal. Secondly, because illness meanings are shared and negotiated, they cannot be considered independently of social networks, social situations

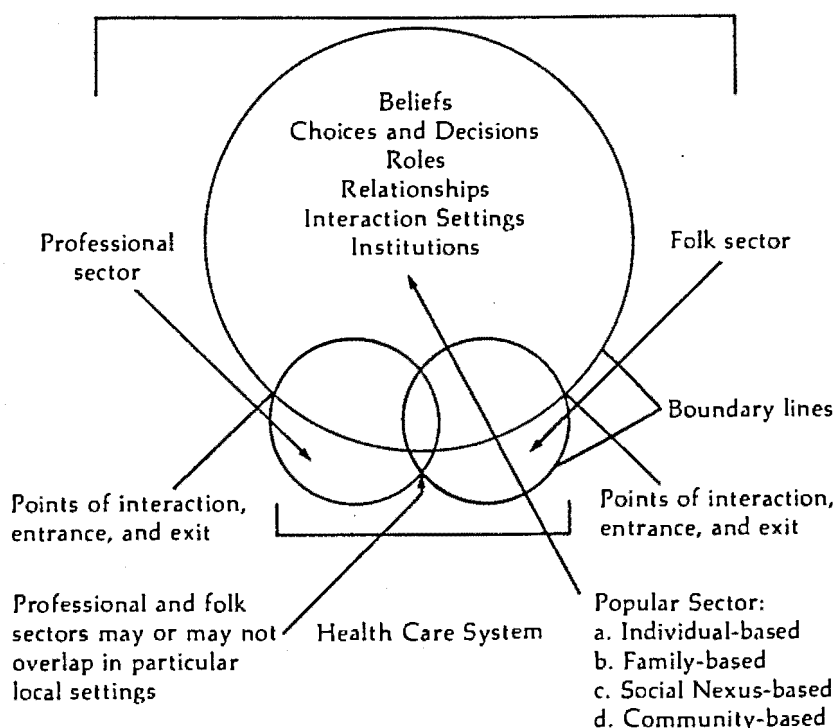
and different forms of social reality.

According to Kleinman (1980), in every culture the experience and treatment of illness, and the social institutions relating to illness are systematically interconnected. The totality of these interrelationships is the health care system. In other words, the health care system, like other cultural systems, integrates the health-related components of society, including socially-legitimated statuses; patterns of belief about the causes of illness; and norms governing choice and evaluation of treatment.

Since illness experiences are culturally and socially embedded, the analysis of caregivers' illness experiences entails a recognition of their different cultural realities. These different cultures - "systems of shared ideas, systems of concepts and rules and meanings that underlie and are expressed in the ways that humans live" (Keesing, 1981, in Helman, 1990, p. 2) - determine the repertoire of narrative resources available to people accounting for an event in a particular time and place, and thus shape the way caregivers describe and explain their experiences, and how they cope with the illness. Caregivers' different cultural orientations will also determine which of the three structural domains of health care in society - professional, popular (family, social network, community) or folk

(nonprofessional healers) - they will approach in order to understand and cope with the illness and the extent to which they will integrate their experiences within these domains with their own beliefs (see Figure 1).

Figure 1. Local health care system: internal structure.



Note. From Patients and healers in the context of culture

(p. 50) by A. Kleinman, 1980, Berkeley: University of California Press.

In Western and non-Western societies between 70 and 90 percent of illness is managed solely within the popular domain, which comprises principally the family context of illness and care and

includes social network and community activities (Kleinman, 1978). Decisions regarding when to seek aid in the other domains, whom to consult, whether to comply, and most lay evaluations of the efficacy of treatment, are made in the popular domain.

The participants in the present study are members of either the Alzheimer's and Related Disorders Association (ARDA) or Stroke Aid, which are both community-based organizations within the popular domain of health care. Caregivers' consultations with nonprofessional healing specialists (such as ministers of religion) occur within the folk sector, while consultations with neurologists, general practitioners, psychologists, speech and occupational therapists occur within the professional domain. Consequently, caregivers, patients and family members are likely to talk about illness in a culture-wide language of experience, whereas professional practitioners do so in their sector-specific language of biological functions and behaviour. Thus, when acknowledging the cultural context of caregivers' illness experiences, one needs to recognise that the knowledge and practice of biomedicine is also culturally embedded. During their training health professionals undergo a form of enculturation as they slowly acquire the 'culture' of their chosen career; their clinical practice of this acquired culture

being influenced by local cultural norms.

Helman (1990) describes culture as an inherited 'lens' through which individuals perceive and understand the world that they inhabit and learn how to live within it. One aspect of this cultural 'lens' is the division of the world and the people within it into different categories. For example, all cultures distinguish between men and women, and the healthy and ill. These categories are laden with different meanings and role expectations. In Western culture, women are traditionally defined as emotional, caring and maternal, whereas men are defined as practical, rational and financial providers. Thus, when a wife is confronted with the chronic illness of her husband, it is perhaps expected that she will be able to cope alone since this is a role that is 'natural' for her. On the other hand, when a husband is faced with his wife's illness, the delegation of the caregiving role to others is considered to be acceptable and understandable. For example, during the second interview with Ann Z., whose husband is a stroke patient, she reflected upon the difficulties faced by male caregivers as a consequence of these cultural expectations. According to Ann, men delegate caregiving duties, because they are not accustomed to "running a home" and when suddenly confronted with this foreign role are likely to have difficulty coping:

I think it is very difficult for the men caregivers, because they probably didn't know anything about running a home and now suddenly they've got to do it. I know the one who comes from Florida - and there is no reason why - but her attitude is: I have had a stroke and I am not going to do anything. So, he had to give up his job, which has now put a financial burden on the whole thing, because she won't even make a cup of tea. She just expects him to do everything, and the last couple of weeks I didn't think he looked well at all. The strain is really telling, of trying to keep - he does a bit of work from home, but with having to do all the housework and the cooking and trying to make a bit of money ... (Stroke caregiver.

Second interview, 4 September 1993)

Implicit in Ann's explanation is the idea that, because women are familiar with the caregiving role prior to the onset of a chronic illness, they are likely to cope more effectively than men as caregivers of chronic illnesses. Further, Ann 'blames' the ill wife to whom she refers, attributing intention to what is reasonable to interpret as adynamia consequent on the stroke: "but her attitude is: I have had a stroke and I am not going to do anything".

Although women may find they are able to adjust to the caregiving role more readily than men in similar positions, the idea that women should be able to cope alone indefinitely when faced with chronic illness (because they are 'natural' caregivers) is a myth, and potentially detrimental to their well-being. Consequently, it is no wonder that the majority of Alzheimer's caregiving studies show that female caregivers experience higher levels of distress and depression than do males in this role (Fitting, Rabins, Lucas & Eastham, 1986; Pruchno & Resch, 1989). The fact that male caregivers experience less distress and depression than female caregivers is not merely because men are more able to set limits on the amount of help they provide and tend to rely more on the support of others to provide care to patients (Biegel, Sales & Schulz, 1991, p. 153), but also because such behaviour on the part of men is sanctioned by society. In the case of women such behaviour is not expected, let alone sanctioned. Biegel, Sales and Schulz (1991) suggest various other variables as possible mediators of caregiving outcomes, such as the nature of the prior relationship between patients and caregivers, social support available to caregivers, and coping strategies used. Paul C., whose wife is an AD patient, explained that men possibly cope better emotionally than women in the caregiving role, because men are used to "stress"

and have been able to develop adequate coping skills over the years: "Most men have had responsible positions and have had stress all their lives and have learnt to cope with it" (AD caregiver. First interview, 25 July 1992).

However, one should be cautious when describing culture as an inherited 'lens', because culture does not have "a free-floating reality independent of any structural constraints" (Brittan & Maynard, 1984, p. 20). Rather, cultural meanings are transformed to fit new developments in technology over time. For example, it was noted in Chapter Three that the development of CAT scans has made it possible to diagnose AD, whereas in the past a diagnosis of AD could only be made post mortem. Thus, technological developments and an increase in the research of AD in recent years have led to a shift in lay people's definition and understanding of AD. For example, Karen N. pointed out during the second interview that "Alzheimer's is a new concept completely" and that in the past it was defined as "senility" and accepted as a normal process of ageing: "You know, Mom just said it was old age, and senility goes with old age" (AD caregiver. Second interview, 4 September 1993). Paul C. also referred to this difference between the conceptualization of AD in the past and present:

Looking back on my early youth, of course it (AD) was present even then and we used to call it "kuns", you know, old age, but it is the same thing. But, I think we recognise it now and of course people are living to a greater age where of course Alzheimer's really does start in the old age. (AD caregiver. First interview, 25 July 1992)

There is thus a dialectical relationship between individual meanings and the wider social organization that is mediated through the medical care encounter (Anderson, Blue & Lau, 1991). Since our social world is thereby linked recursively to our inner experience (Kleinman, 1988b, preface), the exploration of caregivers' experiences will simultaneously entail an analysis of their social worlds; the analysis thereof involving not an experimental science in search of natural law, but an interpretive one in search of meaning.

CHAPTER 5

METHODOLOGY

The aim of this study is to explore caregivers' illness experiences as reflected in their narrative accounts of caring for their ill spouses. Accordingly, in order to retain the qualitative essence of these data, while at the same time systematically analyzing them, a discourse analytic style of inquiry involving the co-construction of narratives by the participants and researcher was regarded as the most appropriate methodological approach.

Interviews

In his critique of the standard approach to interviewing, Mishler (1986) proposes a reformulation of the interviewing process and outlines four premises which were adopted in this study: (a) An interview is a form of discourse, (b) the discourse of interviews is constructed jointly by interviewers and respondents, (c) analysis and interpretation are based on a theory of discourse and meaning, and (d) the meanings of questions and answers are contextually grounded.

Adopting Mishler's (1986) interviewing approach has various implications for this study. Firstly, if an interview is a form of discourse constructed jointly by interviewers and respondents, the interview should be as minimally structured by the researcher as possible to enable respondents to communicate their ideas within their own frames of reference, while at the same time forcing interviewers to acknowledge their own contributions to the resultant dialogue. Secondly, an analysis and discussion of the interview material based on a theory of discourse and meaning would involve a qualitative analysis of the material and specifically a discourse-analytic approach. Thirdly, acceptance of the premise that the meanings of questions and answers are contextually grounded implies that generalisations cannot be made across contexts. In other words, the experiences of caregivers in this study cannot be generalised to all caregivers of stroke and AD. Rather, the idiosyncratic nature of each of the experiences of caregivers in this study should be acknowledged and broad generalisations avoided, because in addition to the meanings of questions and answers being contextually grounded, meanings which co-evolve through social interactions are multiple and shifting, rather than unitary and fixed (Burman, 1991, p. 327).

Two interviews were conducted with each participant. The first interviews were conducted between 28 April 1992 and 25 July 1992. These were unstructured so that the participants' narratives could develop and take their own shape during the interview process and thereby reflect the uniqueness of each spouse's illness experience. However, to ensure that the researcher did not approach each participant in a different manner the initial interviews began with a uniform introductory patter (see Appendix 1), which explained the aim of the study and reassured participants that their confidentiality would be ensured.

Each initial interview was approximately 90 minutes long and all were taped on audio-cassette so that no significant data would be overlooked by the researcher and to facilitate rapport between the participant and researcher. Notes were not made during the interviews since it was assumed that this would interrupt the flow of the narrative process.

After the first interviews had been conducted the tape-recordings of the interviews were transcribed verbatim. These transcripts provided a basis for the structure of the second interviews. These were semi-structured along the lines described below, and conducted approximately 14 months later between

4 September 1993 and 2 November 1993. The assumption was that the second interview would provide an opportunity to elaborate on the narratives co-constructed in the first interview in such a way as to reflect whatever continuities and changes in experience had occurred between the two points of interview. Statements requiring elaboration were identified by analysing the first interviews and selecting vague comments and descriptions which, if explored further, would provide a more in-depth understanding of caregivers' illness experiences and an opportunity for identifying the four layers of illness meaning outlined by Kleinman (1988b). The second interviews were each approximately 60 minutes long and were also taped on audio-cassettes and transcribed verbatim.

Both the first and second interviews were conducted in participants' homes since this was the most convenient context for them. Kleinman (1980) has also suggested that explanatory models are more easily elicited and more accurately reported in the patient's or caregiver's home by a researcher who is not associated with the delivery of medical care. Only one interview, the second interview with a spouse whose wife is an AD patient, was conducted telephonically because he and his wife had moved to Knysna to live with their daughter.

Method of Analysis

A qualitative analysis of interview material was performed using the four levels of illness meaning (symptom, cultural significance, life world, explanation) outlined by Kleinman (1988b) as a framework. Accordingly, it was hypothesized that the caregivers' illness language would be shaped by: (a) Their evaluation of the demands of the situation; (b) the active participation of the researcher and caregivers and their mutual influence in the co-construction of the narratives; and (c) the illness experiences co-constructed in other domains - popular, professional and folk - which incorporate different settings, practices and explanations of illness (Helman, 1990; Kleinman, 1980).

After the first interviews were conducted and transcribed verbatim, each was divided into core themes derived from the text, such as the participant's definition of the illness, description of the onset of the illness, and explanation of its cause. During this process, vague comments and obscure descriptions which were related to the different themes in each text were noted so that the meanings of these statements could be clarified during the second interviews. For example, analysis of the first interview with Ann Z., whose husband is a stroke

stroke patient, revealed that one of the core themes in her particular narrative was the cause of the illness. However, discussion about the cause of her husband's stroke was brief:

RESEARCHER: What kind of stroke was it?

ANN: Well, they have never told me! He
 never ever gave me precisely where the thing
 was and they did brain scans and EEGs.
 (Stroke caregiver. First interview, 5 June
 1992)

Thus, in the second interview with Ann, the researcher enquired about what she believed caused her husband's illness. Although the neurologist never discussed the cause of the stroke with her, it was hypothesised that Ann had probably constructed an explanation of the cause in an attempt to reduce the anxiety consequent on the uncertainty created by her husband's stroke.

The core themes which emerged during the analysis of each of the first interviews were compared, and themes which were prominent in some caregiver's narratives but not in others, noted. The researcher could then, during the second interview, enquire about that particular caregiver's experiences and understanding of the theme, which had not been discussed during the first interview. For example, in most of the first

interviews caregivers related their experiences of encounters they had had with health professionals, such as neurologists. However, this theme did not evolve during the first interview with Peter D., and was therefore noted and discussed during the second interview.

After the second interviews were conducted and transcribed, the researcher once again identified distinctive themes in each of the narratives and compared these with those which had developed during the first interviews. Analysis and comparison of these themes and the language used by the participants enabled the researcher to reflect on the continuities and changes in caregiver's experiences over time.

Participants

To recruit participants for the study, contact was made with the leaders of two different organizations - Stroke Aid and the Alzheimer's Disease and Related Disorders Association (ARDA) - both of which are based in Johannesburg. These leaders were requested by the researcher to inform those of their members who were married to a spouse suffering from Alzheimer's disease or stroke about the study, and to encourage these members' participation. The leader of Stroke Aid provided the researcher

with the names and telephone numbers of five women and four men, caregivers of stroke patients, who were interested in participating in the study. The leaders of two different ARDA support groups reported that two men and two women, whose spouses were diagnosed as suffering from AD, had volunteered to participate in the research and their names and telephone numbers were provided. The volunteers were contacted telephonically by the researcher two weeks later to determine whether they were still interested in participating in the study since they may have reconsidered their participation for various reasons. Four of the volunteers, two widows of stroke victims and two husbands of stroke patients, had decided against participating in the study. The one widow felt it would be too traumatic to revive old and painful experiences, while the other three volunteers claimed that they were too busy to participate in the research. The researcher was unable to contact two of the volunteers telephonically and therefore seven of the 13 volunteers - three men and four women - participated in the study (see Table 1).

Table 1

Summary of respondents and patients.

CAREGIVERS	NAME	AGE OF CAREGIVER	AGE OF PATIENT	YEARS ILL	YEARS MARRIED
STROKE	Ann Z.	64	82	3	35
	Mary X.	68	74	3	50
	Peter D.	76	74	1	42
ALZHEIMER'S DISEASE	Cynthia P.	64	68	10	41
	Karen N.	59	72	16	35
	Paul C. *	75	75	6	49
	Michael A.	81	77	4	53

* Second interview was conducted on the telephone.

Scrutiny of Table 1 shows that the the stroke patients have a generally shorter period of illness than AD patients.

Consequently, AD caregivers are likely to place more emphasis on the mundane, monotonous nature of day-to-day living with an AD patient and their experiences of this problem "without end", such as feelings of loneliness, helplessness and depression. In addition, it is important to note that because the participants are all members of associations devoted to supporting relatives of patients with stroke or AD, they are unlikely to be representative of the caregiver population not served by such organisations. In fact, according to representatives from these

organizations, Stroke Aid has a mere 80 members, whereas ARDA has approximately 690 members. Therefore, it is possible that there are stroke and AD patients and caregivers who are unaware of the existence of these organizations. However, since the aim of this study is to demonstrate an approach to eliciting and understanding the uniqueness of each individual case, this sampling limitation is of less significance than would be the case with quantitative, questionnaire based studies.

The following two chapters present an analysis, discussion and comparison of the spouses' narratives. Chapter Six deals with the caregivers' reconstructions of the interpersonal, behavioural and social damage consequent on their spouses' illnesses, and Chapter Seven deals with their cognitive and practical efforts at repairing this damage. Due to the amount of data collected in the interviews, and for reasons of confidentiality, the transcripts of the interviews have not been provided and the names of the participants have been excluded. Quotations (as recorded verbatim) are used to illustrate the points made in the discussion.

CHAPTER 6

THROUGH THE NARRATIVE WINDOW: DAMAGE AND DECAY

To fully appreciate the sick person's and the family's experience, the clinician must first piece together the illness narrative as it emerges from the patient's and the family's complaints and explanatory models; then he or she must interpret it in light of the different modes of illness meanings - symptom symbols, culturally salient illnesses, personal and social contexts. (Kleinman, 1988b, p. 49)

The aim of this chapter is to discuss the narratives produced through the method described in Chapter Five, and thereby reflect upon their uniqueness and the multiple meanings that radiate from caregivers' illness experiences, while at the same time elucidating similarities between the narratives. Therefore, underlying this discussion is a tension between preserving the idiosyncratic nature of caregivers' experiences and identifying commonalities between the narratives, such as in terms of structure, the themes which evolved during the narrative process, and the language used to describe and explain illness experiences.

Structure

Sequential analysis of the episodes that together make up each initial interview reveals that all involve descriptions of: (a) The patient before and after the the onset of the illness, (b) the extent to which spouses' lives have changed, (c) the way spouses have accommodated to this change and (d) the way health professionals and others have responded to the illness. There are few similarities in the order in which these descriptions were presented. The stroke caregivers initially spoke of the extent to which their lives had changed since the onset of their spouses' illness, whereas the AD caregivers (except for Michael A., who spoke of his support group experiences) began their stories with descriptions of their spouses before and after the onset of AD. This suggests that the sudden occurrence of the stroke was perhaps the most significant of stroke caregivers' experiences, whereas for AD caregivers the extent to which their spouses had deteriorated during the course of the illness seemed to be of greater significance than the pace at which the illness had progressed.

Other structural commonalities between narratives concerned their form rather than sequence. Embedded within the structure of the narratives are multiple stories, which reconstruct events

that occurred either prior to the illness or at different points in the illness course. These stories served different functions. At times they illustrated a particular experience or belief that the caregiver was attempting to communicate, and on other occasions were employed to contextualise a particular event. For example, Peter D. described an incident which occurred "quite a few years back" before his wife had her first stroke, to explain when the doctor discovered she had high blood pressure:

I tell you what happened. Quite a few years back - this goes quite a few years back now - getting into a lift, the lift door closed on her and it threw her against the wall and dislocated her shoulder. And, uh, well, I got a doctor to her and he said, "No, it's just a slight bruising" and that was all. But, about three days later when she was still crying, I got hold of him and I said, "No ways, this isn't that! There must be something more to it." Then he went and had it x-rayed and found it was dislocated. She was lying there for about three days with a dislocated shoulder. Anyway, he referred us to a specialist and when the specialist heard this he tried to get him on the phone. Anyway, I think it was just as well. That's

when they discovered she had high blood pressure.

(Stroke caregiver. First interview, 24 July 1992)

During the course of the initial interviews, caregivers provided few explanations of their illness experiences, and rather focused on descriptions of their experiences. The relative absence of explanations from the initial interviews could be because the caregivers needed to convey the dramatic, disruptive impact of the illness on their lives and thereby convince the researcher of their plight, or a function of previous encounters with health professionals when their experiences were disqualified and considered irrelevant. Thus, the second interviews provided an opportunity for the researcher to explore their explanations and, as described in Chapter Five, vague explanations were noted during the analysis of the first interviews. For example, during the first interview with Ann Z., she reported that the neurosurgeon never told her what type of stroke her husband had had, and described how she challenged the doctor to discharge her husband from hospital, because he was not receiving any treatment: "Well, you know he's just lying in hospital here! He's not having any treatment. What's the point? Why can't I take him home?" (First interview, 5 June 1992). During the second interview, when the researcher

enquired whether Ann had any ideas about what may have caused her husband's stroke, she initially provided a medical description from which flowed her belief that if you harbour "things for years", "you can make yourself ill":

Well, obviously it was a clot. Because, if he had had a hemorrhage, he would have had different symptoms ... Mr Z. does not believe me, but I think he is not a very ... he is not emotional ... he doesn't like discussing things that upset him ... and I think he has been harbouring things for years and I really believe that if you do that you can make yourself ill.
(Second interview, 4 September 1993)

Thus, because the second interviews were more structured, caregivers' explanations of their experiences are more prominent in these interviews. Nevertheless, similarities and differences within caregivers' descriptions of their experiences between the two points of interview do become evident with the second interviews, and portray the ongoing struggle caregivers experience when faced with chronic illness.

Transformations: From Health to Illness

Analysis of the descriptions which emerged in the initial interviews reveals that decisions concerning when and where to seek medical help were made only once symptoms were defined by caregivers themselves as signs of ill health. For example, Peter D. described the onset of his wife's stroke as follows:

Suddenly, I don't know, but for no rhyme nor reason, we were just sitting outside on the back verandah having lunch when she started picking her food with her hands. I said, "What's the matter?", but she was non compos mentis. I took her to the room and got the doctor. He said, "No, get her to the hospital! It's a slight stroke." (First interview, 24 July 1992)

However, Peter did not define the sudden occurrence of this "slight stroke" as a "serious" problem, and to substantiate this belief he explained that, although his wife "couldn't remember" after this "slight stroke", "it was nothing". Peter's use of the word "nothing" suggests that, because his wife's memory impairment was not visible, he did not believe it was a problem:

there was nothing there, there was nothing wrong then. I mean from then until she had this last thing there was nothing wrong; I mean as far as living was

concerned. She could help herself. She did everything for herself. She cooked, she did, the only thing as I say, she couldn't remember, you know, current event sort of things. But, that was nothing, that was nothing. (First interview, 24 July 1992)

In the case of Paul C., he traced the onset of his wife's illness (AD) to "lapses in memory", which only with hindsight did he define as symptoms of an illness:

It's been progressive over some four or five years, I suppose, but gradually the pace increases. The first two or three years one more or less accepted it as more lapses in memory and things like that. Looking back it was obviously the start of this brain disease and it progressively gets worse and worse. (First interview, 25 July 1992)

Thus, both Peter and Paul construed changes in their wives' memories as non-pathological. This could reflect a belief that absent-mindedness is a 'normal' consequence of ageing, or the distinction people in Western cultures make between 'body' and 'soul'; 'illness' being 'body' and 'memory' being 'soul'. Griffith, Griffith and Slovik (1990) refer to the fact that in everyday epistemology, as well as in the specialized vocabularies

of modern medicine and psychiatry, a philosophical dualism between mental and physiological events is readily apparent:

We constantly use language to distinguish mental and physiological domains as we observe the behavior of ourselves or others, and we employ theories, usually implicit, about how the mental and physiological may be interacting to produce the behavior. (Griffith, Griffith & Slovik, 1990, pp. 13-14)

Cynthia P., the wife of an AD patient, also described how during the initial stages of the illness she did not define her husband's behaviour as indicative of disease, but rather as "peculiar", using a story to illustrate her definition:

... but insidiously that not for a minute did I think he was ill or that he had Alzheimer's. I just thought, no, but he's getting most peculiar. We used to have a nice business in town and he was doing peculiar things. I know that I once went overseas to see my children and we had this very nice shop in town and we were expecting the building to come down, and while I was away Mr P. got notice. So, you would think that he would've gotten up and read the papers and looked for new premises. And, what he really did

was - there was a lady who, she actually had nothing to do with our business, she came in as a locum to help while I was away - and he sent her to look for premises and I remember I can't understand this! Why doesn't he go himself? (First interview, 8 July 1992)

Reflecting upon this time preceding her redefinition of his unusual behaviour as signs of disease, Cynthia described the confusion she experienced, and also hinted at a sense of having failed to do everything she might have done to help him:

The first six or seven years were very gradual with just a lot of tensions, because I think I didn't realise he was sick. Like, for example, we'd get in a car and we were going somewhere - say to his sister - and he'd say, " So which way do you want to go?" And I'd say, "What do you mean which way do I want to go? There's only one way to go!" What I didn't realise was that he was saying, "Help me! I don't know which way to go?" Um, so there were a lot of tensions, because one didn't know and neither did he.

(First interview, 8 July 1992)

It was only at the stage when the "silly little things became more major things" - for example, when her husband paid the same

account twice - that Cynthia started to redefine her husband's behaviour as symptoms of disease.

Like Cynthia, Karen N. also defined her husband's behaviour as 'abnormal' at the point when his behaviour had a disruptive effect on their lives. For example, he too was paying the same accounts "two or three times during the month":

As I say this has been thirteen and a half years.

It's a long time. It started off where he had phobias, jealousy about me. You know, I was having an affair with the next door neighbour and this sort of thing. He sort of got lost driving the car and he would have little accidents, because his reaction time wasn't great, you know, and I would find that accounts were being paid two or three times during the month. And that's when I actually took him and we had him tested at the Gen. (Karen N., AD caregiver. First interview, 3 June 1992)

However, caregivers' definitions of their spouses' behaviours as being symptomatic of a disease and their decisions to seek medical advice were not only based on the extent to which their spouses' behaviours were disrupting their lives, as in the case of Cynthia and Karen, but also hinged on the 'normative' expectations of their partners developed during the course of

their marriages, and upon past experience they had had with similar illness. For example, Ann Z. described how the neurosurgeon did not believe that her husband had had a stroke, whereas based on what she had experienced of her sister-in-law's stroke she "recognised it immediately":

And I was rather, more than rather irritated with the neurosurgeon, because I think he thought, he gave me the impression that I was making a fuss about nothing. And first of all, I suppose I was fortunate, this was not the first time I had encountered a stroke, so I recognised it immediately. (First interview, 5 June 1992)

As well as being irritated by the neurosurgeon's refusal to believe her, Ann felt disconfirmed and unfairly excluded from the 'diagnostic' process, arguing that her knowledge of her husband being so much more extensive than that of the neurosurgeon, he should have respected her perceptions:

And I feel that the neuro should have taken notice of what I had observed, after all I've lived with him for years, and I know how he reacts and what he looks like and what he does, but he wasn't interested. (First Interview, 5 June 1992)

Caregivers' descriptions of their partners' behaviours both before and after the onset of the illness not only served to define whether or not their spouses' behaviour was symptomatic of an illness, but also provided an opportunity to explore the impact it had had on their lives. For instance, Michael A., whose wife is an AD patient, spoke of how difficult it was for him to sell the home where he had lived with his wife for 47 years and move into an old age home with her. However, Michael was even more hurt by the fact that, after 52 years of marriage, his wife didn't seem to "care a hell" whether he was "alive or not", and feelings of bitterness, anger and sorrow pervaded his description of her. He thus blamed her for not caring and experienced this as being "worse than her death". This implies that he believed she had some agency or control over her behaviour, whereas her apparent lack of interest in him was a function of emotional blunting consequent on the brain damage:

MICHAEL: But, you must not feel sorry for them. They are not sorry for you. And I have come to learn that this year. She doesn't care a hell if I'm alive or not.

RESEARCHER: From listening to you talking, I think, from the sounds of things, this must have been the most difficult thing for you; the fact that she does not seem to care anymore?

MICHAEL: It's worse than her death ... I feel it is worse. But I am still her husband. (Second Interview, September 1993)

The disconnectedness that Karen N. experienced in relation to her husband, who is an AD patient, resulted in her feeling "terribly, terribly lonely". Although she looked after her grandchildren during the day, it was as though her husband's inability to discuss various issues with her had led to her feeling abandoned. This feeling of abandonment was more deeply felt in the afternoon and evening when she was alone with her husband:

It's terribly terribly lonely, as I can tell you, no matter what - I still look after the kids during the day and that's a big help to me. But, ag, come sort of afternoon and evening, you can't discuss what's going on in the country; you can't discuss family problems. You can't discuss anything. (Second interview, 4 September 1993)

Stroke caregivers also experienced being disconnected from their ill spouses, and Mary X. described how "hard" it was for her to not "discuss anything" with her husband, because she feared he would "completely go to pieces". Thus, she believed that in order to prevent her husband from having another stroke, she had to protect him from any existing and all potential uncertainties:

He can't handle anything and it is hard for me, you know, because I can't discuss anything with him. I can't say to him, "What do you think I should do?", in a certain situation, because, you know, if there is something in the post and as I open it and am staring at it, he asks, "What's the matter? What's the matter?", and I say, "No, it's nothing", and I've got to make up something (Second interview, 11 September 1993).

However, the disconnectedness that caregivers experienced in relation to their ill spouses appeared to be even stronger when they spoke of their relationships with family members, friends and others in their social networks. This social disconnection is explored in the following section.

Social disconnection

Analysis of the narratives reveals that caregivers' experiences of disconnectedness in relation to their children differed to those experienced in relation to other family members and acquaintances. Whereas children were perceived as being disengaged and uninvolved in the caregiving process, acquaintances were construed as prejudiced. Various explanations for this disengagement and prejudice were provided by the caregivers and are now discussed.

Stigmatization

The normal and the stigmatized are not persons but rather perspectives. (Goffman, 1963, p. 138)

In different epochs and societies the cultural significance of symptoms and illness are often of a stigmatizing kind. The term 'stigma', taken from the Greek, means 'to mark or brand' and was originally used to refer to marks that publicly disgraced the person, but in recent times it has been used to refer to disgrace rather than actual bodily marks. Kleinman (1988b) identifies cancer, heart disease and the new venereal epidemics - herpes and AIDS - as disorders which lead to stigmatization in this period in the West. However, the fact that he does not

include stroke and AD among these disorders, does not mean that those who experience stroke and AD do not encounter stigmatization. It is evident from caregivers' narratives that these illnesses do lead to stigmatization and a resultant sense of being ostracised by and disconnected from friends and family members. Illnesses such as leprosy and AIDS were used as metaphors to convey experiences of isolation and stigmatization:

Not one woman (from the bowling club) has come to my house in these two years; come over and said, "How are you?" They're scared; as though you've got leprosy ... Nobody comes. It's like I've got a disease.

(Michael A., AD caregiver. First Interview, 10 June 1992)

Ann Z., whose husband had a stroke, referred to the "extraordinary" fact that the family have "stayed away" and that as a result she could empathise with AIDS sufferers, because her experience of family members' behaviours led to her feeling as though she had AIDS, the plague, or some other infectious disease: "Well, the family are extraordinary. I think I can feel for people who have got AIDS, because you would think we've got the plague or something. The family have just stayed away" (First interview, 5 June 1992). Other caregivers, such as

Mary X., strove to actively maintain contact with friends, but on failing to do so arrived at similarly embittered conclusions regarding the insincerity of "friends":

You know it's very strange. I try and get as many friends of his to come and visit him, but you know, Caroline, it's a funny thing in life - when you lose your money, when you lose your health, you lose your so-called friends. (Mary X., stroke caregiver. First interview, 28 April 1992)

Cynthia P. was also disillusioned with friends, and like Mary, seemed to believe that because "friends" felt that they could not benefit from a friendship with her and her husband, they did not maintain contact with them:

I find them (friends) bad, ja, I find them bad. We have one couple who've remained our friends. For the rest, we sit at home. We were a very gregarious, almost sought-after couple. We both are outgoing. We like people. We had a good social life. We had a good social circle. We were, you know, sought-after sort of thing, and now, you know, we sit home night after night after night. (AD caregiver. First interview, 8 July 1992)

In their attempts to understand this disintegration of previous relationships and estrangement from their social networks, the caregivers constructed different explanations. On the one hand, they saw this as a process set in motion by the perceptions others held of their ill spouses. For example, Karen N. attributed people's avoidance of her and her husband to them feeling "awkward" in the presence of an AD patient, while Paul C. explained that the lack of reciprocity from the AD patient and the patient's inability to recognise acquaintances underlay the dissolution of friendships:

Friends come and see you, but when, I mean your wife doesn't even know them then there isn't much object really in maintaining the friendship is there? You don't come and see people and just sit. There's no exchange. There's no contact at all. So, I mean there isn't much object in them coming so they just stop coming. (First interview, 25 July 1992)

Mary X. explained that her husband's tendency to repeat himself, his limited conversation due to his verbal entrapment in the "old days", and inability to talk about current events, were likely to "irritate" people to the extent that they would not visit him in the future:

None of his friends 'phone him and if I tell you he didn't have dozens, he had hundreds. And nobody phones or comes to see him, because I can see they don't understand and they get irritated. He's got limited conversation. He doesn't know anything about current affairs. He knows that there are a lot of problems and a lot of violence ... He can't really sit and discuss his views about anything. (Second interview, 11 September 1993)

On the other hand, caregivers described how they actively sought to manage closure of family boundaries by preventing interaction with others because it was "embarrassing": "From your point of view as a caregiver you feel embarrassed. So, I think I, from my point of view, tend to limit social activity" (Karen N., AD caregiver. First interview, 3 June 1992). In addition to caregivers feeling "embarrassed", and consequently wanting to protect themselves from future loss of face, they also expressed a need to protect the patient from such situations:

Plus, I don't look for new friends. It's embarrassing! My poor husband can't speak, so he tries to say something and it doesn't want to come out and everybody's sitting listening. Why put him into

such a situation? (Cynthia P., AD caregiver, First interview, 8 July 1992)

Exemplifying how caregivers acted to reduce the amount of social contact by serving as a gatekeeper to the patient, Michael A. described how he shielded his wife from what he considered was the victimisation consequent on her social activities:

She was founder of this (bowling) club. I had to resign her from this club. She used to say, "I can't carry my woods". I put her down second, because she doesn't remember which is her own woods to play and she always plays with somebody else's woods, but I can see the girls resented it. But, girls, you know, women are bitches. They don't say anything to the person, but behind your back they will talk. I had to resign her. It broke my heart - after 20/30 years!
(AD caregiver. First interview, 10 June 1992)

Family Disengagement

Whereas the lack of understanding and antipathy that caregivers experienced from friends was framed in terms of prejudice, the disconnectedness they experienced in relation to their children tended to be construed in less conflictual

terms. For instance, Mary X. attributed the disengagement she experienced in relation to her children to differences in knowledge:

Like you know, he can't use a knife and fork properly, because he gets confused with a knife and fork, you see. So, I cut up his meal and he just sort of uses a fork. And you know, my kids say to me, "Stop it! Don't do that!" But they don't understand that it's not because he can't cut the food; he can't distinguish. You know like you'll give him a plate of soup and he'll take a fork, you know. (Mary X., stroke caregiver. First interview, 28 April 1992)

Incidents such as these led to Mary's decision to discuss various issues with her children as little as possible: "You know, if I say anything - I don't want to say too much - they say, 'Oh, just tell him to stop it. It's enough already!' You see, because they don't understand" (First interview, 28 April 1992).

However, other caregivers were less understanding of their children's attitudes. For example, Michael A. was angry about the seemingly ridiculous advice his children gave him and their apparent insensitivity toward his wife, and was determined that

he was not going to put her in a home as though she was "a dog (that) you put in a kennel":

Now my children want me to be nasty to my wife. They said because I've got my life to lead. I'm 81 and she's 77 and I'm very active. So, they said, "You must go and lead your own life! Her life is gone. She doesn't think she is sick" ... She (his daughter) tells me to get out of the house, but I just can't. So I take the car, I drive around. I go around seven blocks and I come back ... And my daughter says I'm wrong, "Go to a show, take a walk around the block!" Would you like to walk by yourself at six or eight o'clock at night; walk around a couple of blocks by yourself? ... My daughter advised me to put her in a home. It's not like a dog you put in a kennel. (AD caregiver. First interview, 10 June 1992)

During the second interview with Cynthia P., she spoke sadly about the fact that her children "seem to wash their hands of" the caregiving process and that "they're not there", but yet are "great advice-givers":

Cynthia: But, believe me, at the end of the day, the only person who cares is the spouse. Nobody

gives a damn. No children - and I've heard this from a lot of people

Researcher: Yes, yes

Cynthia: Have you as well?

Researcher: In fact from the stroke caregivers as well!

Cynthia: They seem to wash their hands of it!

Researcher: Or they try to help, but they have different ideas of how to help, so arguments develop

Cynthia Yes, yes. Correct. They're not there, they're not around, but they're great advice-givers. (AD caregiver. Second interview, 9 September 1993)

Caregivers constructed different explanations in their attempts to understand such disagreements and disengagement within their families. The most prominent to emerge was that their children have "got their lives to live, which they live" (Karen N., AD caregiver. Second interview, 4 September 1993). Peter D. explained that "most of the burden" of his wife's illness had been on him, because his daughter had "her own life":

The trouble is my wife and I are virtually on our own. We've got a daughter. But she's got her own life and her own children to look after, which makes it a bit

difficult for her to do very much - plus a full time job - which means, you know, that most of the burden has been on me. (Stroke caregiver. First interview, 24 July 1992)

Another explanation provided by Mary X. to make sense of the fact that her children were uninvolved in the care of their father after his stroke, was the effect of the patient's illness behaviour on the children: "You know, my daughter is very nervous. In fact, she was at the nursing home the one day when he was absolutely demented. You know, she had to put herself to bed with tranquillizers for two days" (First interview, 28 April 1992).

Cynthia P. and Karen N. (AD caregivers) also attributed the unsupportive behaviour of their children's to the nature of their children's relationships with the ill parent in the past:

Cynthia: And my young son I'm very bitter about, because he's got everything going for him and about a year or half a year ago I said to him, "Really, I need a bit of help. Just once a month or once in six weeks, come and take Daddy away and just get him off my back for an afternoon". And they just don't - nothing.

Researcher: Could a possible reason be that they saw the way their father was towards you - very demanding - and that's also affected their compassion in a way?

Cynthia: Maybe. I've also thought that just as he was a lousy husband, he was a lousy father. So, I thought to myself - what did he ever do for them? But, then I think to myself that I'm not asking them to do it for him. I'm asking for me! (AD caregiver. First interview, 8 July 1992)

Unlike Cynthia who was obviously bitter about the fact that her "young son" did not respond to her request that he take his father "off (her) back for an afternoon", Karen seemed to feel betrayed by her daughter's devotion to her father in that "she absolutely worships the ground he walks on", and appeared to give up hope that her children would "show that kind of caring and support" she so desperately needed:

If the kids would come to support group meetings ...
I see other people and they have their kids come with them. You know, it shows that kind of caring and support, but I don't get that from my children ... And

my daughter thinks to this day that I am very hard on Mr N. She absolutely worships the ground he walks on and I don't think she will ever understand until such time as she personally has to look after him and whether that time will ever come I don't know. So, from that point of view I don't get support from the kids. I've got to make major decisions myself. (Karen N., AD caregiver. Second interview, 4 September 1993)

The disagreements between Karen and her children regarding the care of Mr N. have led to her children defining her as "hard and unsympathetic". Distraught and frustrated by this definition, Karen interpreted this response from her children as an indication of their denial that their father is ill and their lack of knowledge about AD:

They just think that I am very hard and unsympathetic and I don't know how to get through to them to try and study it. I don't know. Well, I've come to the conclusion that they actually don't want to face reality. They want to try and remember Mr N. as he was - an efficient headmaster, a science man ... a pole-vaulter in his heyday ... They can't accept what

he has become. (AD caregiver. Second interview, 4 September 1993)

Cynthia also explained how the lack of reciprocity from the AD patient could be a contributing factor in her children's non-participation in the care of her husband:

It is very difficult, because you cannot have a relationship with these people. You cannot! Even our little three year old grandson knows that when he speaks to grandpa, it's different to speaking to other people. (Second interview, 9 September 1993)

Cynthia also drew upon the idea that there are gender specific roles. It seems that this idea was based on her experiences of sons' and daughters' attendance at support group meetings. She accounted for attendance differences as follows:

It's difficult for the boy who's got, after all, a wife and family, whereas a daughter is different ... Daughters are totally different. I can see in our support group - the ladies that have got daughters - the daughters always go with to the group. My son came once with me and he said, ag, he doesn't see that there's anything there for him. (First interview, 8 July 1992)

Exploitation

Although all the caregivers experienced being disconnected from family members and friends, some did have occasional contact with relatives, but did not regard this contact as being for the sake of friendship. For instance, Ann Z. believed that the contact she had with her family after her husband's stroke was purely for utilitarian reasons, because they would "only come when they wanted something". This belief was confirmed during a conversation with her sister, who seemed to feel guilty about not having contacted Ann more frequently after Mr Z's stroke: "My family have only come when they want something ... And actually my sister said to me, 'This sounds awful. It sounds as though I only 'phone when I want something'. So, I said, 'Well, you said it and not me!'" (First interview, 5 June 1992).

Other caregivers, such as Cynthia P. and Karen N., spoke of how their children would request that they look after the grandchildren, thus exploiting their domestic entrapment. However, their children framed these requests in positive terms and seemed to believe that they were being helpful to their caregiving parents; a belief which was not shared with the caregivers. For instance, although Cynthia acknowledged that it was "lovely" to see her grandson, she felt that this did not help

in caring for her husband: "You know, they think that if they bring their little boy here, then that's a lovely outing for us. Well, it's lovely to have the little boy, but that's not helping me in terms of their father" (Cynthia P., AD caregiver. First interview, 8 July 1992). Feelings of exploitation were more evident in Karen's case, because when she requested anything from her children she would "always get the impression the children are too busy", and yet she was always prepared to help when they requested anything from her:

Last week I asked my son to buy a soccerball for me and I asked him to please drop it off after 'varsity on Tuesday. Well, yesterday was Friday and, because I had the kids and I was working in their garden - always doing things for them - I was still there when he came home. He took the ball out of the car and gave it to me. To them it is unimportant, but to me - they just don't have the time to do things for me. (AD caregiver. Second interview, 4 September 1993)

During the first interview with Peter D., he spoke of the considerable effort he and his wife had made over the years to help various family members when they were experiencing problems, and how these members had "never bothered" to help them after his

wife's stroke. He was hurt, angry and disillusioned by this lack of concern and was determined that he would not allow them to exploit him or his wife in the future:

Well, I'm the hell in. No ways will they get anything out of me! I know damn well that if anything happens to her and she died they're gonna come and say, "Oh well, what about this? What about that?" They can jump in the lake. Not one of them will get a damn thing! Not a thing! ... I was actually feeling so fed up the other day and I said to the girl the other day, "You know, all these people, they mustn't come around my house afterwards, because I'll chase them." I said, "I don't want them here." (First interview, 24 July 1992)

Authenticity and Uncertainty

In contrast to the caregivers of stroke victims, AD caregivers have to deal with feelings of anxiety consequent upon etiological uncertainty. People also tend to question the authenticity of AD caregivers' experiences, because (particularly in the early stages of AD) there are no physically visible symptoms of the disease. However, in the case of stroke, hemiplegia and aphasia are noticeable: "But, when you look at

her everybody says, 'Look, you're talking nonsense!' They don't believe what I'm going through" (Michael A., AD caregiver. First interview, 10 June 1992).

This questioning of the authenticity of AD caregivers' experiences led to them developing an enhanced sensitivity of and vigilance toward the reactions and perceptions of people with whom they came into contact. For some, this led to the adoption of an abrupt and defensive posture toward others. For instance, Paul C. was hesitant when discussing his experiences with the researcher, and the implicit message was 'ask your questions and then leave'. For others, it cued intense attempts to convince people of the 'reality' of their experiences, as did Karen N., who in the first interview (before even hearing why the researcher was interested in her story), began to speak of her concern about the impression that the AD "patient gives towards the outsider". The researcher found this comment interesting, because she had been speaking to Karen's husband while waiting for Karen to arrive for the interview. It was as though Karen had been carefully scanning the researcher's responses to ascertain whether once again the validity of her experiences would be questioned, and taking steps to ensure that her experiences would be verified by the researcher. She thus proceeded to describe her husband's behaviour and the type of

person he was both in the past and in the present in her attempt to convince the researcher of the reality of her husband's illness:

There is one thing that is very worrying to a caregiver, and that is the impression that the patient gives towards the outsider. They are very good actors, and you know, they can put up a front; especially a person like Mr N. He was brilliant. I mean he was a school teacher. He was deputy principal of a high school, head of science, head of geography, taught all the rugby etcetera, etcetera ... And he was a laypreacher in the church. So, you know, his ability to express himself makes it difficult for the outsider to understand that there is actually something wrong ... It makes me angry inside, because you know, people think that I'm bluffing. (First interview, 3 June 1992)

Karen then told a story of how her husband had got lost whilst on an outing with other senior citizens to the Southgate Mall, to illustrate the torturous path she had to travel before others would acknowledge that her husband was ill and that she was not "bluffing".

People's responses to AD also seem to be shaped by the fact that the cause of AD is uncertain. For example, Paul C. said that his wife's illness is "frightening the hell" out of his daughters, because his "wife's brother had the same problem, so they worry that it's genetic" (First interview, 25 July 1992).

Damage and Destruction

The overall impression gained from the caregivers' narratives, was that of worlds - personal and social - devastated by the potent influence of AD and stroke. Lipowski (1979) identifies five categories of personal meanings of illness - illness as an enemy, as a weakness, as punishment, as loss or damage, and as a challenge. All the caregivers seem to have experienced the chronic illness of their spouses as loss or damage, hence the emphasis in their descriptions of their spouses's positive attributes prior to the illness, which in certain cases led to outright romanticisation. For example, Mary X. described her husband as a "wizard" and "an absolute genius with figures" prior to his stroke:

He was a bookmaker and he was a wizard, a genius with figures and money and quick, but so quick. You can't believe it! I mean he didn't need a calculator. He

would just look and work out percentages. He was an absolute genius with figures and now he doesn't even know what a cent is or a rand is. Money is ... So, you know, one day he was doing what they call a settling of R20 000 and the next day it's all gone.

(First interview, 28 April 1992)

Karen N. described her husband as "meticulous" before the onset of his illness (AD) and, although he had "always remained a gentleman", was "a completely different man to the man (she) married":

He was meticulous. He is a completely different man to the man I married. I don't know this man at all! The only thing that I am grateful for is he is never nasty. He has never become aggressive. He has always remained a gentleman, which I am terribly grateful for. (Second interview, 4 September 1993)

Michael A., whose wife is an AD patient, described how his wife's ability to "play a wonderful game of tennis" and "a lovely game of bridge" had "just faded away" as the illness has progressed: "She used to play a wonderful game of tennis. She used to play a lovely game of bridge. All that has just faded away. All in the last two years" (Michael A., AD caregiver. First interview, 10 June 1992).

However, when illness is seen as punishment, Lipowski (1979) points out that emotional reactions may reflect passive resignation and angry depression. For example, Karen N. spoke at considerable length during the second interview about problems she was experiencing with her children and seemed angry and depressed when she questioned whether the suffering she was experiencing in relation to her husband's illness could be due to 'mistakes' she had made in the past concerning her children: "I just wonder with myself. Am I being punished for all these things?" (Second interview, 4 September 1993).

Accommodation

Caregivers' lives, like those of the patients, were drastically altered by the damaging effects of these illnesses. For some caregivers accommodation to the aftermath of the illness was sudden, and for others it was a gradual process. Paul C., whose wife is an AD patient found he had to "curtail his activities" and that he became "more and more housebound" as the illness progressed:

My wife used to be a very vital person and a very important partner in my life - both business and social - and now of course, with this onset of this disease, she is quite incapable of making any

contribution to anything. And, whereas she was an exquisite cook and a great hostess, these things have all gone. Not quite so bad as the fact that with her problems she's very unhappy if I am away, and it's not always that easy to be here all the time, with the result is one's got to curtail your activities. One becomes more and more housebound as time goes on. In addition, of course, you can't carry on any intelligent conversation. There's nothing at all!

(Paul C., AD caregiver. First interview, 25 July 1992)

Paul's description exemplifies the gradual accommodation the AD caregiver has to make as the disease progresses. By contrast, and consistent with Rolland's (1988) distinction between the immediate accommodation necessary in the case of stroke and the gradual accommodation in the case of AD, Mary X's account of the impact that her husband's stroke had upon her life illustrates the sudden accommodation she had to make when the stroke occurred:

I was the secretary of a very big fund-raising organization. I ran the whole organization and I worked very, very hard. In fact it was beginning to

get too much, because I was doing everything - the transport, the fund-raising, the everything ... I only worked in the morning ... I sort of did what I had to do and came home at four o' clock and did my cooking and whatever ... In one day my whole life changed. I had to stop work instantly! He wouldn't stay in the nursing home. He carried on so much there, because he didn't know where he was! (Mary X., stroke caregiver. First interview, 28 April 1992)

Common to both Paul's and Mary's accounts is the loss of freedom they experienced as a result of the demands placed on them by the patients. In Mary's case, these demands were of such a nature that she had to immediately give up her job, whereas Paul could continue to pursue his interests and gradually "curtail" them as his wife's disease progressed to render her increasingly incapacitated.

In addition to changes in their behaviour and social patterns, caregivers' narratives also suggested the degree to which their world views were confirmed during the illness course. According to Sluzki (1983), each of us interacts with our environment according to a privately held world view, which organises "raw reality" and serves as the basis for perception,

the attribution of meaning and action. For instance, during the first interview with Ann Z., it was evident that her belief that each individual within a family should be independent and have "their own space to do their own thing" was confirmed during the period of her husband's illness:

I think the whole thing is I'm not used to this clinging, because before his stroke he pretty well went his way, I went my way, and with having only one child I was terrified that I would make her a clinging child. So, I made her frightfully independent and so, of course, she also did her own thing. So, it was a case of three people living in the same house - we had lots in common and we did things together - but at the same time everyone had their own space to do their own thing. And, now I have this clinging, which I never had even with a child ... I find it extremely irritating ... I'm very much in favour of making children independent and ... they've got to make their own decisions and when they make the wrong decisions they've got to take the consequences. So, this clinging drives me scatty! (First interview, 5 June 1992)

Thus, the more Ann experienced her husband's dependent behaviour as "clinging", the more determined she was that she was not going to compromise her own personal time:

He didn't like it at first, but I said to him, "When I go upstairs I don't want to hear of you". I don't care what he wants, he can wait! There's got to be some cut-off point at which that is my time and I'm not going to be interrupted. (First interview, 5 June 1992)

Entrapment

Implicit in caregivers' descriptions of the extent to which they have had to accommodate to these illnesses are feelings of entrapment and helplessness. While Peter D. was able to maintain some sense of agency and mastery over the situation when his wife was in hospital after her first stroke, her return home left "nothing else" for him to do, creating a sense of entrapment and futility:

There's no two ways about that - things have changed considerably. I mean, you know, from the very first day she's had that stroke it's a case of going to the hospital, visiting her in hospital, coming home, going back ... But it has sort of changed my life a lot in

that there's nothing else I can do. There's nowhere I can go, nothing I can do (Peter D., stroke caregiver. First interview, 24 July 1992)

This theme of entrapment was elaborated by Mary X., who described how her husband's dependence pervaded even the most intimate recesses of her life-world:

RESEARCHER: He's very dependent on you?

MARY: But utterly and completely!

RESEARCHER: So it must have been quite difficult for you, because you were quite free in the sense that you had your job and you could get in your car and do your own thing?

MARY: Correct. And he used to do his own thing.

RESEARCHER: And now suddenly you have been flung together. You have to be together all the time.

MARY: Twenty-four hours a day! The only time I have is like on a Tuesday. I do a grocery order for myself and my daughter, and I can't let him sit at the shop 'cos it takes over an hour, so my maid comes and she stays here ... When I go to a shop I know he's sitting outside, so I'm rushing to get out.

When I go to the bath, he says: "Don't be long!" When I go to the toilet (he says): "Don't be long!" I mean he's like my shadow. He's like a Siamese twin. (Mary X, stroke caregiver. First interview, 28 April 1992)

The loss of freedom and resulting experience of entrapment is highlighted by caregivers' use of metaphors. Mary's description of her husband's dependence on her ("shadow", "Siamese twin") vividly portrayed the extent to which her freedom has been compromised by his illness, and Ann Z., described how she felt like a "prisoner" in her own home: "But, you get to a point where you feel that you're a prisoner in your own home" (Stroke caregiver. First interview, 5 June 1992).

Multiple Problems

Whether an illness necessitates instantaneous accommodation (as in stroke) or progressive accommodation (as in AD), the restructuring of caregivers' lives is not a static event. During the year between the first and second interviews, two of the stroke caregivers' spouses had experienced further strokes, necessitating that once again these caregivers restructure

their lives in an attempt to create some order from this further fragmentation. For instance, Ann Z. found that she had to employ a nurse during the day, and Peter D. decided to employ nurses to look after his wife both during the day and night until she experienced a third, fatal stroke. Thus, the restructuring of caregivers' lives is an ongoing process, which is reflexively shaped by the course of the illness.

The events of everyday life, such as financial obligations and the problems which arise in daily life, also contribute to this restructuring process. For example, caregivers are often solely responsible for making financial decisions, a situation at times in stark contrast to the shared earning and decision making that preceded the illness:

He planned no finances, no policies, no insurance, no nothing. I had to start from scratch ... I've had to work, because his income is, you know, being medically retired before time and ag, it was before the new dispensation etcetera. So we lost out terribly financially. (Karen N., AD caregiver. First interview, 3 June 1992)

Cynthia P. described that she would "worry a great deal", because she was the "sole breadwinner for two people", but that she had decided to "get on with it and do the best" she could:

I worry about the future, because I'm the sole breadwinner for two people (my son who is not working, and my husband). So I worry a great deal, but to a large extent I have now decided that worrying is not going to help me. I must just get on with it and do the best I can. (AD caregiver. First interview, 8 July 1992)

In addition to caregivers being solely responsible for making financial decisions, they often have to face other difficulties and illnesses which occur in their family systems. For instance, Cynthia P. spoke of the fact that her oldest son has a "drug-induced schizophrenia", and during the first interview with Mary X., she spoke of her one daughter's traumatic divorce and her other daughter's hysterectomy. In the second interview (17 months later) Mary described the "rough time" she had had since the first interview:

I've just had a rough time. My son-in-law had a double hernia operation and a week later he had a heart attack. He is only 50! A week after that he had to have a triple-bypass ... And we got a terrible shock with my son. He collapsed (he lives in England) and, to cut a long story short, they did brain scans

and they found something on the brain. I tell you, I have been going quite beserk. (Mary X, stroke caregiver. Second interview, 11 September 1993)

In order to protect her husband from this "terrible shock", because she believed "he would completely go to pieces" and "would have had another stroke", Mary decided to "hide everything" from him by adopting different roles which were alien to her 'real' self: "I became the proverbial liar and an actress, because when I heard it I could not stop crying. So, I would go in the bathroom and cry, come out and put a big grin on my face" (Second interview, 11 September 1993). However, Mary believed that she herself was being shielded from her son's illness by her children, who kept "as much as possible away" from her. It worried her to be "in the dark", because she would "rather know the worst" than experience anxiety as a result of the uncertainty. Although Mary seemed to play a central role within her family, she explained that her "whole life revolves around" her husband:

Like in the morning, the first thing he says to me is "What are we doing today? and I cannot say, "Nothing", so what I do is I plan. I try and plan a week in advance, so I'd say, "Well, we're going here

today" ... and as I say my whole life revolves around him. (Mary X, stroke caregiver. Second interview, 11 September 1993)

The narratives also suggested that unresolved conflicts experienced with children in the past may be re-ignited during the course of a chronic illness. For example, Karen N. spoke of her adopted daughter's "basic mistrust" of her and the difficulty she has communicating with her adopted son about her husband:

He has got an answer to everything - some very logical answers too. I am actually scared. I am scared to open my mouth. I get twisted round in little circles. Even when I know I am right - inwardly - but he will make me feel that I am totally wrong. (AD caregiver. Second interview, 4 September 1993)

Thus, it is clear that what evolved during the various interviews were not merely accounts of discrete illness experiences, but stories of lives in which the illness itself had become an integral aspect of the caregivers' lives:

The trajectory of chronic illness assimilates to a life course, contributing so intimately to the development of a particular life that illness becomes inescapable from life history. (Kleinman, 1988b, p. 8)

Summary

Discussion of the structure of the narratives, caregivers' illness language and various themes which emerged - such as, disconnection, multiple problems, authenticity and uncertainty - has highlighted similarities and differences in caregivers' experiences. This has enabled one to look through the narrative window and thereby gain some perspective on the damage and destruction of caregivers' lives by chronic illness, and the "terribly, terribly lonely" and complex nature of the caregiving process. Although this analysis reveals that similarities in caregivers' experiences outweigh differences, a prominent theme that evolved in AD caregivers' stories - authenticity - unveils an important difference between AD and stroke caregivers' experiences. During the initial stages of AD, caregiving spouses' observations are not only disbelieved or minimised by family members and friends, but are ignored by health professionals. Consequently, they struggle along in their day-to-day lives, amidst feelings of uncertainty and confusion regarding their ill spouse's behaviour. The implications of this for professional care are discussed in Chapter Eight.

CHAPTER 7

COGNITIVE REPARATION: ATTEMPTS TO MEND THE DAMAGE

The identification and discussion of themes in Chapter Six dealt primarily with caregivers' accounts of how family boundaries and social interaction patterns were influenced by stroke and AD. In this chapter the focus is on conceptual changes and caregivers' attempts at repairing the damage experienced during the course of these illnesses. More specifically, explanatory models constructed in response to numerous questions regarding the illness and its treatment, and the extent to which these models were shaped by encounters with health professionals, community-based organizations and the media, is explored.

Explanatory Models

During the course of chronic illness, explanatory accounts are constructed by patients and their relatives in response to a number of different questions they have regarding the various aspects of illness and treatment. In Chapter Four, the concept of EMs was discussed and it was argued that they "are essential

for the more immediate tactics of tacking through the rough seas of chronic illness" (Kleinman, 1988b, p.48). The degree to which EMs provide the cognitive structure in which illness experiences are contained and dealt with, is now investigated.

Cause

Stroke caregivers. Although Peter D., Mary X., and Ann Z. provided medical explanations for the cause of their spouses' strokes, they also provided their own personal explanations for these events. Peter explained that his wife had high blood pressure and regretted that this was not detected sooner - "Actually I think that was a problem which we didn't discover early enough" (First interview, 24 July 1992). Later during the first interview, he attributed the occurrence of stroke to "the pace of life today" and explained that it is for this same reason that he "takes things in (his) stride":

Actually it's the pace of life today which is bringing it on all the time. It's the pace of life. That's why I say I'm glad to a point that I sort of take things in my stride and don't worry what's going to happen in 10 years time or in 5 years time, or even tomorrow. (First interview, 24 July 1992)

Mary X. explained that her husband's stroke was due to a "clot" and that the doctors wanted to operate on his carotid artery "because they reckon that that's where the clots are coming (from)". However, she believed he would not have survived the operation, and inferring from their diagnosis that the root cause was "thick blood", attempted to rather "keep his blood fairly thin" by using her "common sense with the Warfarin":

They wanted to do an angiogram and they wanted to operate on his carotid artery. But he was ... there was just no way that he could ever, ever have survived that operation. My house-doctor still says he should have it done. But, I mean he would never cope with it. I know he could never cope with it! ... But, I feel, you know, I'm keeping his blood fairly thin.

(First interview, 28 April 1992)

Apart from Mary's medical explanation for her husband's stroke, she believed that her husband had a stroke, because "some idiot" told him that if he did not take his medication he would feel "like a new person" and being a "soft person" he stopped taking his tablets:

Some idiot - because you know, he is a very soft sort of a person and you can talk him into anything - said to him, "You know, if you threw away all your

medicines like me, you would feel like a new person". So, I used to give him his medicine and as I turned my back, he would put it in his pocket and that was when he had a proper stroke! (First interview, 28 April 1992)

Ann Z. also explained that her husband's stroke was caused by a "clot", "because if he had had a hemorrhage he would have had different symptoms". However, she felt that her husband blamed her for his illness, and in turn she blamed him, because she believed that "he has been harbouring things for years" and by doing that had made himself ill:

I think it might be common with stroke people - I don't know what you found - but they try and blame someone for having had the stroke. Now as far as I am concerned, he is responsible for his stroke - nobody else - and if he wants to get better it is up to him. Nobody can do it for him. You know, I can do much, but in the end that is all I can do. I think he blames me. (Second interview, 4 September 1993)

Ann then elaborated on her theory that if you "harbour things for years ... you can make yourself sick", as follows:

And when you build up all these resentments, I don't see how your body can work with all these closed

circuits ... all these things blocking up inside, because as far as I am concerned, the brain is rather like an electrical system and if the messages aren't getting through, something has got to give ... And I think these resentments built up through his life from a young child, and never talking to anybody about it ... (Second interview, 4 September 1993)

Ann has attempted to confirm this theory by speaking to other wives whose husbands are stroke patients, and discovered other explanations for the cause of stroke, such as "violent temper":

I've tried to talk to some of the other wives about how their husbands were before. The one woman said her husband had the most violent temper before he had the stroke and it was the temper that finally gave him the stroke, but since the stroke he has calmed down completely. (Second interview, 4 September 1993)

Ann's causal explanation for stroke is similar to that of other wives, because both explanations concern 'pressure' and its control. However, at another level these explanations differ in that Ann attributes the cause of stroke to a build up of internal 'pressure', whereas other wives believe that stroke is caused by the release of too much 'pressure'. Ann believed that her husband had a stroke, because he had built up resentments over

the years and had not spoken to anyone about them. Thus, she believed the internal 'pressure' created by this build up and the fact that this 'pressure' was not released, led to her husband's stroke. Other wives believed that stroke is caused by a violent temper. This suggests that inadequate, internal control of emotions, and hence frequent release of too much 'pressure' through rage outbursts, causes stroke.

Thus, although medical explanations have been incorporated into these stroke caregivers' EMs, it is evident that they have their own personal explanations about what caused their spouse's stroke. The theme of blame was prominent in their explanations: Peter seemed to blame both himself and the doctors for not discovering "early enough" that his wife had high blood pressure, Mary blamed her husband for being "soft" and listening to an "idiot", and Ann blamed her husband for "harbouring things for years".

AD caregivers. Although the theme of blame was less prominent in AD caregivers' explanations, Cynthia P. held her husband responsible for "letting himself get so sick" and was angry and bitter when she spoke of the fact that she "grieves" for herself more than she does for him:

I just grieve for the state of my life now. I am cross with him for letting himself get so sick, because all his life - you can see all his books here - he has always maintained that ... you control your mind. Whatever you - he was a Freudian, absolutely - and whatever you wanted. Now I'm sitting - "And so what are you letting yourself get like this for? Where's your mind now?" (First interview, 8 July 1992)

The scientific uncertainty as to the cause of AD was replicated in AD caregivers explanations. Nevertheless, it was clear that their EMs, like those of the stroke caregivers, involved both medical explanations and their own personal theories. For example, Michael A. attributed the onset of his wife's illness to the death of his son:

I lost a son three years ago, four years ago. She hasn't shed a tear. I think that must have started it in her brain, you see. You know, if you keep it in, keep it in. She doesn't mention his name. (First interview, 10 June 1992)

Later in the interview, he provided a 'medical' explanation for his wife's symptoms:

She had two CAT scans and they found out she's got a little spasm in the brain - a little space - and as soon as it touches that space, she'll go off the deep end. Then she'll say, "Get out the house". How many times she has chased me out the house. (First interview, 10 June 1992)

Michael's belief that "if you keep it (grief) in" it is likely to affect you, is similar to Ann Z's belief that "if you harbour things ... you can make yourself ill" and suggests that AD and stroke caregivers may share the very common belief that if people do not express their emotions, they are likely to experience these illnesses. Paul C. believed that AD is most likely due to "stress", which is similar to Peter D's belief that the occurrence of stroke is due to "the pace of life today". This suggests that "stress" might also be a causal explanation shared by stroke and AD caregivers.

The idea that the pressure and stresses of modern life cause illness can be traced back to 1897 when the famous physician, Sir William Osler, warned that the worry and strain of modern life, and the high pressure at which men live, caused 'arterial degeneration'. This fear of modernity, and its effect on the heart was once again evident when the cardiologists, Friedman and

Rosenman (1959) proposed the Type A and Type B model of human behaviour. This model was constructed to explain the rising incidence of coronary heart disease, and it was proposed that the Type A individual was more prone to suffering from heart disease than the Type B individual. Friedman and Rosenman (1959) described the six core features of the Type A Behaviour Pattern as follows: (a) An intense, sustained drive to achieve self-selected but usually poorly defined goals, (b) a profound eagerness to compete, (c) a persistent desire for recognition and advancement, (d) a continuous involvement in 'multiple and diverse functions' constantly subject to deadlines, (e) a tendency to accelerate the rate of many physical and mental functions, and (f) an extraordinary mental and physical alertness. By contrast, the Type B individual is described as a relaxed, laid-back, friendly and non-competitive person, who is satisfied with his status and a life centred mainly on the circle of his family and friends (Helman, 1991, p. 127).

Helman (1991) points out that in the USA heart disease still has its own symbolic significance, and has even acquired its own mythology: "In our modern minds, heart attacks have a relationship to what we do, as if we bring them upon ourselves" (p. 136). Analysis of caregivers' causal explanations for stroke

and AD indicates that these illnesses have also acquired their own mythology, because caregivers' constructions indicate that they believe that their ill spouses brought these illnesses upon themselves; patients themselves are responsible for their suffering.

Unlike the other caregivers, Karen N. did not appear to have her own personal theory about the cause of her husband's illness, and her explanations drew upon what she knew about research into the causes of AD. While speaking about theories, she seemed to favour the idea that AD is hereditary, because she believed that her mother-in-law had AD and that this would explain her husband's illness:

I don't know if it is something we have done wrong in our early years. Lots of people have said that cooking in aluminium pots - but how many millions of people cooked in aluminium pots? Until that is sort of proven definitely, who is to say? I really don't know, and I think there is a certain amount of hereditary aspect to the thing, because Mr N's mom, I am sure, had Alzheimers. She was very strange, and definitely senile. (Second interview, 4 September 1993)

Encounters with medical practitioners

While explaining their beliefs about the cause of their spouses' illnesses, caregivers also described their encounters with medical practitioners. In Chapter One, I discussed the fact that Ann Z. and Cynthia P. felt disqualified and unsupported by the doctors whom they consulted, and that they felt frustrated at not being able to breach the barrier between them and these medical professionals. However, all the caregivers, not only Cynthia and Ann, described their encounters with medical practitioners in negative terms.

The AD caregivers appeared to be frustrated by the fact that doctors "know nothing" about the illness. For example, Paul C. was irritated by the conflicting information he received from different doctors and needed their "encouragement", but did not receive that either:

They know nothing about it and they just guess - can't give any help at all. They give no encouragement either. They know nothing about it ... I think you get three doctors - one says this, another says it might be and another says it's going to be. (First interview, 25 July 1992)

Karen N. experienced the neurologist she went to as being "very blunt", and Michael A. was exasperated by the fact that "you don't get anybody here that can advise you. You go to the doctor ... I've spoken to three specialists and my doctors and they say, 'We don't know!'" (First interview, 10 June 1992).

The stroke caregivers described the impersonal nature of their contact with specialists and doctors, as follows:

RESEARCHER: Did you have regular contact with your GP ?

PETER: No. At Millpark it was always the specialist. Our GP never even came near me after she had the stroke. I put her in hospital and that was the last time he worried about her.

RESEARCHER: Very impersonal.

PETER: It was. Even when I called him it was a bit of a job to get him, although, eventually, when I did ask him to come, he would come without too much of an argument. But to start with he was not all that helpful.

RESEARCHER: And the specialists? How did you find them?

PETER: Well, the one specialist that she was under at Millpark Hospital, I don't know, I hardly

ever saw him really. Every time I bumped into him he would give me a bit of information, but nothing more. And that was that. He would just give me information of how she was getting on or if she was not getting on, but further than that - nothing!
(Second interview, 11 September 1993)

Analysis of the narratives reveals that in addition to caregivers requiring explanations for their spouses' illnesses, they need advice, encouragement and understanding during the consultation. Furthermore, they need the practitioner to show ongoing concern and support during the course of the illness. Ann Z. explained how she thought that if her husband's neurosurgeon was a "concerned doctor", he would have "picked up the 'phone and said, 'I did not see him for a check-up. How is he?'" (First interview, 5 June 1992). Based on the "churlish treatment" she experienced from the neurosurgeon, and the "off-hand" manner of the neurosurgeons in general, Ann decided she would rather take her husband to their GP for future check-ups. She explained that her GP "seldom keeps (them) waiting", would always "fit (her husband) in" when he did not have an appointment and that she could "rely on Dr G. at any time".

Mary X. said that although the hospital staff were "very nice", she found that there was not "that personal care" and "each time you go you see another doctor". Therefore, rather than sitting "at casualty for hours and hours" she would take her husband to have a check-up with their "house-doctor" once a year. In their search to understand and cope with their spouses' illnesses, it appears that caregivers' were largely frustrated by encounters with medical practitioners. Due to futile attempts at dissolving barriers between themselves and different practitioners they approached Stroke Aid or ARDA in the hope that these organizations would be of help to them. Thus, their experiences as members of Stroke Aid or ARDA were elicited to determine to what extent membership of these organizations satisfied their needs. AD caregivers tended to be negative about their experiences at ARDA support group meetings, whereas stroke caregivers were more favourable toward Stroke Aid.

Alzheimer's and Related Disorders Association

AD caregivers, Michael A. and Karen N., believed that support group meetings "are not always the answer", because there was too much diversity in these groups and that the groups were "a bit big". They explained that groups included not only AD caregivers, but also caregivers of people with related disorders,

such as Parkinson's disease. Furthermore, both children and spouses are included in the same group:

Each one's got a different thing entirely. This one talks about Parkinson's and this - if I had to talk and say something it would mean nothing to them, because it doesn't help them. Neither does it help me, because they can't help me and we're all in the same boat; we're about 10 or 12 of us. (Michael A. First interview, 10 June 1992)

Michael explained later during the interview that support group meetings provided an opportunity to "get away from it all" and to express his feelings, but was dissatisfied because he needed advice and "they can't give advice":

But, they do nothing for you. Their mother doesn't say hello to them, she doesn't recognise them. So, they come to these meetings to get away from it all ... we have a gathering. It's an outing. I can express my feelings in front of everybody, but they can't give me advice, and neither can I give them advice. (First interview, 10 June 1992)

Karen N. also found the composition of groups too diverse, as well as stifling her needs to talk and be heard:

But you know they are not always the answer. I have been going to this group for many years ... The group - I think it is a bit big for one thing - they used to break up into married couples or children and parents ... now it is just mixed ... One woman dominated the entire meeting with her own problems ... There is no control ... Instead of saying, "Listen, let the other people have a chance." (Second interview, 4 September 1993)

Like Karen N., Cynthia P. felt frustrated by the fact that "one or two persons dominate the group" and believed that the group leader could not "cope with it" and "was not trained in any way for this sort of work":

We have one somewhat hysterical woman in our group. She spoils the whole tone ... She should be shut up nicely and let other people also get on with - but she laughs and she's got this hysterical, you know, and the group leader doesn't cope with it ... The therapist should be able to say, "Let's hear. Look, here's a new person". Now and then we have a new person who doesn't have a chance to speak. (Cynthia P. Second interview, 9 September 1993)

Cynthia explained that because she is "inclined to be a bit bossy" she would "sometimes sort of interfere" when frustrated by the situation: "I am inclined to be a bit bossy ... I sometimes sort of interfere, because I cannot stand being frustrated. There we have got a new person and I sometimes say, 'Why don't we hear what S. has got to say?'" (Second interview, 9 September 1993). Nevertheless, Cynthia spoke of the fact that it was "pleasant to just get away for an hour" and described her experiences with various members of her group:

But it is still, as I think it is for all of us, pleasant to just get away for an hour, pleasant to hear that everyone has the same problems ... There are definitely friendships. I have become quite friendly with one of the ladies. We went out a few weeks ago - she and her husband and mine. It was pleasant. And, there are some that I can't stomach - I keep away from - because they irritate me and I am sure it works like that in groups. (Second interview, 9 September 1993)

Apart from requiring that the group leader take control and allow more members to contribute at each meeting, Cynthia believed that she could benefit from "some sort of intellectual stimulation".

However, by saying this she did not mean that she needed educational input, because she felt she was an 'expert' on AD:

What I would like with the support groups is guest lecturers - people who can give one some sort of intellectual stimulation ... Not educational. I know everything there is to know about Alzheimer's. I have read every note. But, just a doctor, a neurologist, a psychiatrist, somebody who's got some fresh ideas; who speaks well. It would be nice. (Second interview, 9 September 1993)

Like Michael A. and Karen N., Paul C. also implied that support groups have limited value for caregivers, because "all they can do is give some sort of back-up support", and he described how it was "quite frightening" to meet caregivers who were dealing with patients in "more advanced" stages of the illness:

Well, I think all they can do is give some sort of back-up support, that's all. I mean encouragement and you hear other people having the same problems you're having and, uh, well, it's also quite frightening, because you meet people who are far more advanced and it gets to worry one a bit. (First interview, 25 July 1992)

Despite feeling negative or neutral about support group meetings, caregivers continued to attend such meetings. Both Michael A. and Cynthia P. construed this as an opportunity to "get away" from the dull routine of their daily lives, and to identify with others who were "in the same boat" as them. Nevertheless, they concurred that the utility of support group meetings would be enhanced if group leaders considered a number of factors. Firstly, group leaders should offer practical advice about how caregivers could provide care for patients. Secondly, group leaders should create opportunities during group meetings for all caregivers to contribute to the discussion. Caregivers also believed that they could benefit from intellectual stimulation, such as lectures by health professionals. Finally, caregivers' stated that groups should be small and homogenous. In other words, there should be separate groups for spouses and children.

Stroke Aid

Stroke caregivers' experiences of their contact with Stroke Aid seemed to be more favourable than AD caregivers' experiences of ARDA. Ann Z., Peter D., and Mary X. spoke of the benefit their spouses derived from occupational therapy and physiotherapy provided by Stroke Aid. Although Mary acknowledged that her

husband had benefited from therapy at Stroke Aid, she compared the general lack of facilities for stroke care in South Africa with the more abundant facilities available in the USA:

Oh, that Stroke Aid is wonderful, but it is only one morning a week. He enjoys it and they are actually giving them something to do ... They sort of give them what they call brainteasers. Look, some he can cope with, some he can't, but he likes it there. You see, unfortunately in this country there isn't a single - like they have Stroke Aid - that's it! There's nothing in this country! In America they've got these clinics in every suburb, day clinics, hour clinics, which is absolutely wonderful. Psychologists, psychiatrists, but there's nothing here. There's absolutely nothing for this type of condition. (Mary X. First interview, 28 April 1992)

Thus, although Mary believed that Stroke Aid was a "wonderful" organization and that her husband had benefited from the therapy they provided, it was clear that she believed that the services provided by Stroke Aid were limited and insufficient compared to those available in the USA. During the second interview she spoke again about the fact that her husband had benefited from the therapy provided by Stroke Aid, because "he's with others in

the same situation, so he doesn't feel inferior; he doesn't feel inadequate", and she still felt it was "a pity" that meetings were held only once a week.

Ann Z. spoke of how Stroke Aid has served different functions during the course of her husband's rehabilitation. Initially he attended the weekly meeting for physiotherapy, but later Ann made use of this opportunity to have time for herself:

Now we go for a different reason, because I wasn't getting any time at all on my own. So now, I leave him there at half past nine and I pick him up at twelve o' clock. So, that gives me those couple of hours on a Tuesday morning. (First interview, 5 June 1992)

Peter D. mentioned that he found Stroke Aid "very good" in helping him cope with his wife's illness, because they gave him practical ideas of how to help her and offered their impressions of his wife's condition which helped him to verify observations he had made:

Stroke Aid are very good. I like them. That lady she goes to is very helpful with her and she gives me ideas of what I should do and what I shouldn't do to try and help her along ... And the lady said, you know, no, she could see that she was going backwards. (First interview, 24 July 1992)

Thus, a number of factors seem to have played a role in shaping the extent to which caregivers' found Stroke Aid helpful in dealing with their spouse's illness: The fact that their partners had benefited from therapy, practical advice about how to cope with their spouses' impairments, and the opportunity for caregivers to have some time for themselves.

Media

A common theme to emerge from the caregivers' narratives is their need for practical advice about how to cope with their spouses' illnesses. However, it is evident that this need was met neither in their contact with medical practitioners nor during their participation in support group meetings held by Stroke Aid and ARDA. Some caregivers therefore relied on other sources for this advice, such as books and the radio. During the first interview with Mary X., she spoke of "the most wonderful book" she had "just read" and that she would "keep reading it over" in an effort to cope with the difficulties her husband had experienced since his stroke:

I just read the most wonderful book. It is called The 36 Hour Day and I've learnt so much about dementia. It's all sort of related to one another and I've

learnt a lot from this book ... and I'll keep reading it over. There's lots of things that I've been doing that I shouldn't do. You know, he'll say something ten times, but you mustn't say, "But I've already told you", because he doesn't know that he's even asked you the question and you've got to try and change the subject. (First interview, 28 April 1992)

During the second interview, Mary referred to this book once again, and said that she believed it was "the only thing that has really helped" her. Thus, although this book is a practical guide for AD caregivers, Mary felt it was helpful to her in terms of how she should cope with her husband's stroke, because she believed her husband's illness was AD's "cousin":

The only thing that has really helped me, was this book ... What my husband has got is a cousin, I would say. I have asked the doctors when they have done his brain scans and he definitely has not got Alzheimer's. But, his condition is so related to Alzheimer's in so many aspects. It's quite amazing! (Second interview, 11 September 1993)

Michael A. also spoke of a "wonderful book" he received from his daughter in the USA, which told him what he should do when caring

for his wife who has AD. In fact this book played such an important role in assisting him with the day-to-day care of his wife that he felt he could not "let it go out of (his) hands":

This, believe you me, it's a wonderful book. I can't let it go out of my hands. You can photostat it if you want ... Sometimes something happens and I want to refer to it. So, right away it's a reference. They give examples here. Like my wife won't bath and they tell you exactly how to bath them. All little things - say the person gets annoyed, aggravated. They tell you what to do. (First interview, 10 June 1992)

Other caregivers, such as Ann Z., found the radio helpful in providing information and giving advice. In Ann's case, it was through a radio programme that she heard about Stroke Aid, and she was angry that this organization had not been recommended to her whilst her husband was in hospital:

Fortunately I listen to everything on the radio, and at some stage they were interviewing somebody from Stroke Aid and I took their name and number down in my emergency list of people I may need at some stage. Now, there again I think at the hospital they should have said there is this organization, instead of which

he was just discharged and they didn't say what I should do or what treatment he should have or anything like that. (Stroke caregiver. First interview, 5 June 1992)

During the second interview, Ann explained that she taped a programme on the radio so that her husband could listen to the discussion, because she found that very often he would not listen to her, but would listen to somebody else:

702 get these people in and very often you learn more from when people 'phone in and then the speaker gives the answer. And, oddly enough, there was someone on last night on the David Blood show. I taped it, because I have been saying to Mr Z. all along, "You have to take responsibility for yourself". I think everybody has to. But, here was somebody else - and very often what I say is in and out and that's it straight through - but when somebody else says it, then it makes a difference. (Stroke caregiver. Second interview, 4 September 1993)

Thus, the media - books and the radio - were used by some caregivers' to obtain advice about how to cope with their spouses' illnesses, to get in contact with other sources of

information and, at times, to convince their ill spouses about their beliefs.

Psychotherapy

Only two of the seven caregivers, Cynthia P. and Karen N., who are both AD caregivers, had experienced psychotherapy. Cynthia explained that she had "been seeing a psychologist for many years", because her son was diagnosed as suffering from schizophrenia, and Karen attended therapy at a local hospital during the course of her husband's illness, because she was "terribly depressed". Cynthia explained how her therapist had framed her husband's illness as having "liberated" her, because prior to the illness, he was a "very, very difficult man". Cynthia thus distinguished herself from other AD caregivers by saying that she was a "rather atypical example", because she did not have to "deal with the grief at losing this loved person" like others in her group had:

Mine's a rather atypical example, because I was married to a very, very difficult man. He was extremely autocratic ... I used to have to plead and beg for every cent that I got. So, I had a hard life with him ... I have been seeing a psychologist for

many years and she put it very succinctly. The way she describes it, is his illness has liberated me, because I'm now the one who holds the purse strings ... By the time he got sick I don't think I loved him very much any more. So, I notice when we go to the Alzheimer's groups, one of the things that a lot of the people have to deal with is the grief at losing this loved person, you know, this person they so loved. That's an emotion I haven't had. So, I don't really grieve.

(First interview, 8 July 1992)

Cynthia's use of the past tense when speaking of her husband implies that he is dead, whereas he is still alive. This suggests that while the patient is being transformed by the disease, so too does the caregiver's conceptualization of the patient change. Cynthia no longer believed that her husband was difficult or autocratic, and therefore agreed with the psychologist's reframe that the illness had "liberated her". Thus, in this case the transformation of the patient was interpreted in positive terms, whereas in most cases this change is usually experienced as traumatic; the "social death" experienced by family members in relation to the patient causing much heartache and grief. The researcher was curious about

whether Cynthia believed she was coping with her husband's illness as a consequence of having been in therapy, and explored this with her:

RESEARCHER: So, would you say one of the reasons why you're coping is because you've been going to therapy for quite a few years and you've perhaps learnt to deal with things differently and work through them?

CYNTHIA: I can't answer you. I can't answer you. I don't know. I don't know whether it's by nature of my personality which is somewhat dominant. I'm a dominant sort of - I'm not a cowering ... But, the reason I'm coping, I think, is because I am a capable person. I'm good at the business. I've been able to just take it over. (First interview, 8 July 1992)

Nevertheless, it was clear during the interviews with Cynthia that psychotherapy had had a considerable impact on the way she spoke about and explained various experiences. For instance, at the end of the first interview when the researcher thanked Cynthia for her participation in the study, she spoke of her experience of the interview as being "like a catharsis":

RESEARCHER: So, I'm glad you helped me out. I really appreciate it.

CYNTHIA: No. It's nice for me too, because when one talks you -

RESEARCHER: You need an outlet. You get a lot off your shoulders.

CYNTHIA: It's like a catharsis, yes, yes.

(First interview, 8 July 1992)

During the second interview, Cynthia also seemed to believe that her support group could benefit from the presence of a psychologist, because "there was one stage when (she) went to the the group that a psychologist came with the group leader" and she felt it was a "more meaningful sort of group". Therefore, later during the interview, she asked the researcher to attend one of their meetings.

Unlike Cynthia's experience of long-term therapy, Karen's therapy was brief, because her therapist had "got her over" her desperation "so much so that (she) thought (she) could do without his help", and implied that she felt she needed his help once again:

He was extremely good and I was terribly depressed ...

There were times I really considered driving to a hospital and booking myself in. I was so desperate, you know. But, he got me over that. So much so that

I thought I could do without his help ... But I think one needs that sort of therapy sometimes. (Second interview, 4 September 1993)

Summary

It is clear from the above discussion that caregivers' attempts to repair and reconstruct their lives were hampered by their dissatisfactory encounters with medical practitioners and by the fact that their needs were not completely met by community-based organizations. In addition, their attempts to mend their damaged lives were hindered by multiple problems which were discussed in Chapter Six. These problems, such as financial difficulties and other family members' illnesses, served to shape their experiences further. Thus, caregivers' illness experiences were not just a function of the illness, but were also influenced by social factors.

In general, consideration of these spouses' constructions of the caregiving process depicted it as a mundane, monotonous, and grey process. Except for Cynthia P. who constructed her experience in terms of a positive reframe provided by her therapist ("the way she describes it, is his illness has liberated me"), none of the caregivers suggested that the

experience of stroke or AD could be perceived as "good" or as a "growth experience". Instead, their narratives produced an image of decay as they witnessed both the 'decomposition' of their spouses and the dilapidation and disintegration of their own lives. Nevertheless, the caregivers showed determination and perseverance when faced with these various adversities, and perhaps it was this strength and determination which helped them to survive the ordeal.

CHAPTER 8

EVALUATION OF THE STUDY AND IMPLICATIONS FOR FUTURE CARE

A critique of the study

In using narrative analysis with the interview responses of caregivers' illness experiences, certain advantages and disadvantages over more traditional methods, such as the questionnaire, were found.

Disadvantages

Analysis of oral narratives is a slow process, and therefore not a suitable method when there are time constraints. Secondly, during the co-construction of caregivers' illness experiences, narratives are shaped by the researcher's ideas and are further moulded by the researcher during their analysis. For example, in this study the researcher identified a number of common themes, such as social disconnection, authenticity and entrapment. Due to the complex, detailed nature of the stories, additional themes may have been overlooked. Furthermore, other researchers may have abstracted different themes to those identified in this study.

The analysis of written biographies is perhaps a more appropriate method of narrative analysis when there are time limitations, and may reduce the degree to which participants' experiences are influenced by the researchers' contributions. However, the analysis of written experiences also involves the researcher imposing his or her own constructions on the interview material during the analytic process. Thus, the findings and conclusions derived through narrative analysis are "temporary constructions" (Gergen in Antaki, 1988, p. 110) shaped by the context of narration and analysis. Findings in this study cannot therefore be generalised to all caregivers who are spouses of stroke or AD patients.

Advantages

In Chapter One, the metaphor of a one-way mirror was used to convey the nature of the medical practitioner-patient relationship, and it was proposed that through attention to caregivers' illness experiences, this mirror could be replaced by a window. In other words, rather than health professionals focusing on the language of disease and ignoring the language of illness, they should consider the illness experiences of patients and caregivers. Such consideration may aid diagnosis, reduce the occurrence of conflict and encourage the development of more

mutual, supportive and empowering relationships between patients and professionals. During the interviews, not only was a narrative window on AD and stroke caregivers' experiences constructed, but the collaborative nature of the interview process was respectful of the participants and provided an opportunity for them to be heard. According to Viney (1989), social scientists often need to take on the role of speaking for those who participate in social science research, and especially in relation to illness, where the voices of patients are relatively rarely heard. In addition to the researcher creating a context for caregivers' to voice their experiences, an attempt was made to reproduce these experiences in a minimally distorted manner. Interpretations which might have negated the participants' experiences were therefore avoided. Furthermore, the unstructured nature of the interviews enabled the researcher to validate caregivers' experiences, because as Kleinman (1988b) points out, it is important for the health professional "to witness a life story, to validate its interpretation and to affirm its value" (p. 50). Thus, caregivers generally evaluated the interviews in a positive light, and not as an intrusion. This encouraged caregivers to share their intimate thoughts and feelings about illness, and resulted in their narratives being elaborate and rich in detail.

Having discussed some of the advantages and disadvantages of narrative analysis, it seems that for studies which aim to construct the experience of chronic illness, the advantages of this method outweigh the disadvantages. Thus, in future studies of chronic illness experiences, this method would be valuable. It is important that future research of chronic illness be conducted, because chronic illness not only invades the patient's life, but consumes the energy and resources of the patient's family. Future studies would therefore assist those professionals who treat chronic illness to understand the complex nature of illness experience, and be more effective in providing care. More specifically, medical practitioners need to be sensitized to the concepts of illness and disease, and the importance of eliciting and witnessing patients' narratives.

Implications for future care

The feelings of social disconnection, loss, loneliness and depression which emerged in these narratives are only a few of the various experiences which could be addressed by health professionals, particularly psychotherapists. The discussion of the themes in Chapter Six has various implications for therapists, because understanding these themes alerts one to

significant aspects of caregivers' experiences and thereby enables one to make appropriate therapeutic decisions. For example, in the case of an AD caregivers' support group, one may choose to create a context where participants' stories are witnessed, acknowledged, and most importantly, authenticated. In the case of a stroke caregivers' support group, the therapist may choose to explore the sudden impact that the stroke had on participants' lives and elicit ideas about how they could restructure their lives. It is hypothesized that gender differences would also have implications for how therapists conduct group meetings.

Anderson, Blue and Lau (1991) point out that women's experiences cannot be subsumed under those of men, because there are specific issues, such as women's roles inside and outside the home, which influence a woman's experience of illness. However, analysis of the narratives indicates few major differences between women and men's caregiving experiences. The most significant difference was in the way that men and women spoke about their experiences. Male caregivers tended to provide more factual descriptions, whereas women portrayed their experiences in more vivid, metaphorical terms. For example, Cynthia P. described her experience of her husband's behaviour as "like having a child tagging along" and explained that "he needs to be

looked after like a baby". Karen N., whose husband is also an AD patient, described him as being "like an obedient little puppy dog with the mentality of a two year old. Even less, because a two year old will give you a bit of lip". Mary X. explained that her husband "carried on like a demented animal" in the hospital after he had had his stroke and that he was so dependent on her that he was "like a Siamese twin".

Another gender difference which became evident during the second interviews, was that women appear more able to sustain and persevere with the caregiving role than men who are in the same position: Paul C. and his wife moved to Knysna to live with their daughter, Michael A. sold his home and moved into an old age home with his wife, and Peter D. employed nurses to help him care for his wife after she had had a second stroke. In comparison, the caregiving wives had made few changes to the structure of their lives, and continued to endure alone difficulties which arose and the monotony of the caregiving process. None of the women had moved home, and Karen N., Mary X., and Cynthia P. were still central in their families' activities. Although Ann Z. employed a day nurse after her husband had experienced another stroke, she received no other help in caring for him. These differences could be because women

are more familiar than men with the nurturing role, or because this is what is expected of them. A few of the caregivers (such as Cynthia P.) seemed to believe that daughters are more supportive of the caregiver than sons, who are generally uninvolved. However, analysis of the interviews indicates that this was not necessarily the case. For instance, Karen N. mentioned that her daughter disagreed with her caregiving ideas and had a "basic mistrust" of her, and as a result felt she did not receive the support she needed from her daughter. In fact, the male caregivers seemed to receive considerable help and support from their daughters, whereas women caregivers found that their daughters were either largely uninvolved in the caregiving process because they had their own lives to lead, or were unable to help in the care of their fathers because they lived far away.

However, there were generally few gender differences which could be because these caregivers are elderly and therefore accept the occurrence of chronic illness as an inevitable part of the ageing process. Although the resounding message is clear - "there's no two ways about it, it (chronic illness) changes your life dramatically" - the impact of the illnesses on their lives is almost certainly less than if the caregivers had still been rearing children and attempting to establish careers.

However, based on the researcher's recent experiences of ARDA support group meetings, most caregivers had never contemplated psychotherapy and were unable to distinguish between the roles of psychiatrists and psychologists. This suggests that chronic illness is an area where the voices of therapists have not been heard. This may be due to a preference for more 'dramatic' problems, such as suicide or sexual abuse, or perhaps because the knowledge that chronic illness cannot be cured leads to feelings of helplessness and negativity on the part of the therapist.

Often when we see devastated families in which a child is dying of cancer, or a beloved parent is slowly receding into the shadow of Alzheimer's, we feel our own impotence before human quandries that cannot be resolved by any amount of therapeutic ingenuity.

(McDaniel, Hepworth & Doherty, 1993, p. 63)

In fact, the "quest for cure is a dangerous myth that serves patient and practitioner poorly. It distracts their attention from step-by-step behaviours that lessen suffering, even if they do not magically heal the disease" (Kleinman, 1988b, p. 229). Although therapists cannot cure chronic illness, they have a vital role to play in helping patients and caregivers with the problems created by the disease, such as loss and loneliness.

Despite this, most people who are faced with chronic illness are elderly pensioners, and therefore psychologists cannot expect them to be able to afford individual psychotherapy. Thus, if psychologists offer their services to community-based organizations, such as Stroke Aid or ARDA, they could make a significant difference to the care provided by these organizations. In addition, therapists in training could practice their skills and gain valuable experience of group therapy should they become involved in such organizations. This would in turn, help those organizations that depend on volunteers for help.

However, according to McDaniel, Hepworth and Doherty (1993), therapists who have worked with those experiencing chronic illness, have tended to regard medical problems as secondary to the 'real' issues of interpersonal interaction. Family therapy theories can therefore actually block an adequate understanding of a client's real dilemma. Rather than therapists ignoring the impact of the illness on people's lives, McDaniel, Hepworth and Doherty (1993) define the therapist's role in the area of chronic illness, as follows:

The job of the medical family therapist is more to bear witness than to intervene, to listen and encourage families to tell their own stories, find their own meanings in the calamity that has forever altered them. Not that this is so very different from what all family therapists do, but the stakes are higher. Illness and death, as perhaps nothing else, take us to the very edge of human extremity. (p. 63)

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APPENDIX

FIRST INTERVIEW - INTRODUCTORY PATTERN

As I mentioned to you on the 'phone, I am interested in talking with you about how you've experienced your husband's/wife's illness, because I believe that if health professionals have a more in-depth understanding of this they could perhaps be more understanding and useful to people, like yourself. I haven't got any set questions, because I am interested in your way of relating to your husband's/wife's illness. I will also not take notes during our discussion, but will rather tape this interview so that I don't overlook any important information. Once I've talked with other caregivers, I will listen to the tape of this interview and only then will I think of a few questions which I might have regarding this conversation and will contact you to make another appointment for a second interview. When I report my findings I will at times quote verbatim from different sections of the interviews, but I won't reveal your name at any point in the discussion, so you needn't worry about people being able to identify that it was you who said a particular thing.

So, perhaps we could start where you feel most comfortable, and go on from there?