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A systems analysis of the employment problems of
people with epilepsy.

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Thesis submitted for the degree of
Doctor of Philosophy

City University

Rehabilitation Resource Centre
Department of Systems Science

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Terminology

Throughout this thesis the term 'epileptic' is only used where it is a direct quotation. Otherwise 'people with epilepsy' is used to imply, firstly, that it is the seizure and not the person which is epileptic and, secondly, to highlight that it is the seizures which are the problem and not other aspects of the person.

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ABSTRACT

The study investigated the relationships between epilepsy and employment. A comprehensive and critical literature review is presented, leading to the development of a biopsychosocial framework of medical, psychosocial and occupational factors. Relationships suggested by the literature were empirically tested in three samples of employed people with epilepsy in two major UK organisations. Methods included postal questionnaires, interviews and document analysis.

Empirical evidence showed two types of outcome: employment problems and career problems. These outcomes were related to different aspects of the framework. Employment problems related to seizure control aspects and psychosocial factors outside work and career problems related to characteristics of the epilepsy itself and psychosocial factors inside work. A biopsychosocial model of epilepsy in the work-place was developed from the empirical work which identifies points of intervention and is discussed in relation to the law of requisite variety (Ashby, 1964).

Conclusions and future research are identified in the area of management practice. Important aspects of this study are the development of a biopsychosocial model and the conceptualisation of epilepsy as a management resource issue.

PART ONE INTRODUCTION

- Chapter 1 Introduction and aims of the thesis
- Chapter 2 What is epilepsy?

CHAPTER ONE

INTRODUCTION AND AIMS OF THE THESIS

Contents

1.0	Overview
1.1	Disability as a challenge to society
1.2	The importance of economic integration
1.3	Disability and economic integration
1.4	Epilepsy and economic integration
1.4. 1	Epilepsy and unemployment
2	Epilepsy and job difficulties
1.5	Aims and structure
1.6	Objectives

1.0 Overview

This chapter will discuss the importance of economic integration to us as people within a society. This will be contrasted with the experiences of people with disabilities who are often restricted in their working lives due to discrimination or a lack of understanding about their abilities and their capabilities for various types of work. The chapter will continue by focusing on epilepsy as a specific employment problem and conclude by setting out the research needs, aims and objectives of this thesis.

1.1 Disability as a challenge to society

Firstly, it must be stated that disability is of much wider concern to the community than might first appear. About 10% of the population

experience a significant degree of physical or mental impairment at some time in their lives (Daunt, 1991); disability is an issue of importance to many people.

The problems faced by people with disabilities are very real and non-trivial. Not so long ago common knowledge of disability was obscured by medical jargon and its reality was sheltered by the privacy of the family, or hidden behind the walls of hospitals or asylums. Many of these barriers of concealment have come down in order to enable people to live in the community. With these barriers has gone the legitimacy of ignorance; disability is now undeniably and irreversibly in the public domain (Daunt, 1991).

Since the 1940s, there has been a growing amount of legislation in European countries aimed at promoting the training and employment of people with disabilities. Since the end of the 1960s, the notion that there should be positive action for the employment of disabled people has become firmly established in most countries. Added to this is the rise of the 'disabled movement' which recognised independent living as a right of disabled people and economic activity as a means towards this. There is now increasing emphasis by

national and international organisations on the promotion of vocational rehabilitation for people with disabilities.

Disability management then, as a human resource issue, is concerned with making people productive and providing a means by which people with a disability can be active within their community. As such, the economic integration of people with disabilities constitutes a challenge to society.

1.2 The importance of economic integration

Why is economic integration so important? The importance of work to an individual may be seen on several levels. Writers on this subject have emphasised not only the economic, but also the social and psychological benefits (Maslow, 1954; Argyle, 1972). It is suggested that an individual has a strong need for status and a useful function (Brown, 1954), and that this can be obtained from work (Jahoda, 1958; Warr, 1987). It is also suggested that this cannot be obtained to the same extent from other aspects of our lives (Ling, 1954). Employment, in this sense, defines and determines who we are and our role in society (Peters, 1962).

1.3 Disability and economic integration

In competition for employment, people with disabilities have fared less well than people without disabilities (United Nations, 1988). It has also been recognised that this need not be the case and that people with disabilities should be able to obtain work that is within their capabilities and make a valued contribution to society (Tomlinson Committee, 1943).

In the UK the Tomlinson committee, set up in 1943 to look at the issues of vocational rehabilitation for people with disabilities, made certain key assumptions which are still relevant today and guide policy in this area. These are:

- 1) that most people with disabilities, once they have been rehabilitated, are no different in employment terms from other people. Not only are they just as productive, but their needs are no different and they can, and should, be treated in exactly the same way as other employees;
- 2) that only a very small proportion of disabled people cannot be rehabilitated and will continue to be significantly handicapped as far as employment is concerned (Tomlinson Committee, 1943).

This view has been formally recognised in the UK since the 1944 Disabled Persons (Employment) Act.

However, forty years after the Act was brought into force the success of attempts to improve the employment situation for people with disabilities has been limited (Kettle, 1984). It has been pointed out that the Act "...fails to acknowledge that difficulties can arise not only at the recruitment stage ... but also once they (people with disabilities) are in the job" (Smith et al 1991). The problems people with disabilities face at work are, therefore, not being adequately addressed. The crucial questions of where difficulties arise and how they can be avoided or overcome is difficult to answer because there has been a lack of employment-based research on people with disabilities.

1.4 Epilepsy and economic integration

The problem affects all types of disability but one group which finds employment a particularly difficult and problematic area is that of people with epilepsy. Let us now look at what is known about the economic integration of people with epilepsy.

The impact of epilepsy is perhaps felt most acutely in the area of work, for it has been said that, for people with epilepsy, "...work, especially if it brings economic security,

provides not only an interest but instils a desirable sense of independence and a responsibility which favours and facilitates proper social adjustment" (p673: Cohen, 1958). Studies have shown that people with epilepsy view employment as the major indicator of successful integration with society (Bahrs & Ritter 1988).

Rehabilitation of the person with epilepsy usually involves vocational adjustment more than any other form of rehabilitation (Quadfasel & Guhleman 1952) and people with epilepsy are considered to be among the most difficult people to place in work (Patterson, 1962). Employment then is a real problem for people with epilepsy.

It is particularly important to look at the employment problems of people with epilepsy because most people with epilepsy are fully employable (Gering & Copping 1980) and have no demonstrable disability or difference when they are not having a seizure. Indeed no-one should be unemployable because of seizures alone (Pond & Bidwell, 1960; Dominion et al, 1963; Jones, 1965). Let us look at two employment problems that might arise: unemployment and job difficulties.

"Of what use is it to rid the person of fits,...
if he remains an economic invalid because he
is denied the right to work"
(p1693; Lennox & Markham, 1953)

It has been said that for the adult with epilepsy, unemployment is the most serious problem they have to face (Masland, 1985). An early study of unemployment was conducted by Lennox and Cobb in 1942. In this study of over 1000 people with epilepsy of working age, Lennox and Cobb (1942) found that the majority of the subjects were unemployed and only a quarter to a third of these were actually unemployable.

In the inaugural lecture in a series sponsored by the organisation 'Opportunities for the Disabled' given at the Faculty of Occupational Medicine (McLellan, 1986), it was said that the American companies who barred employment to applicants with disabilities were more likely to discriminate against people with epilepsy or a visual impairment than any other disability.

Approximately 70% of employers excluded people with epilepsy across a wide range of different types of work. In the same paper, McLellan (1986) refers to a survey of employers in the Southampton area which showed that a person with epilepsy is

less likely to be employed than someone with chronic bronchitis, heart disease, diabetes, or someone with a visual or mobility problem. The survey found that 42% of employers believed that they did not have jobs that could be filled by someone with epilepsy, compared with only 20% of employers who did not have jobs for all the other categories of disability (McLellan 1986).

Much of the literature on epilepsy and employment attempts to draw conclusions about the level of unemployment. (The problem with deriving these statistics will be examined in Chapter Two.) The quoted rates vary widely both between and within studies, as the following example unemployment rates show: 25% (Holmes & McWilliams 1985); 21% to 37% (Gerstle de Pasquet E 1984); 25% to 42% (McLellan 1986); and 53.4% (Walker 1957). For individuals with more severe or frequent seizures, unemployment rates are quoted to range from approximately 50% (Goodglass et al., 1963; Rodin et al., 1972) up to 76% (Gerstle de Pasquet, 1984). As you can see, there is very little agreement on this rate.

Taking figures from the Office of Health Economics (1971) as an example of this research, it is found that about 30% of the people with epilepsy of

working age are employed and an equivalent figure will not be job ready (they may for example be having very frequent and severe seizures). This gives us an unemployment figure of about 40%. This is an alarming figure worthy of study in itself. However, it is misleading to think of complete unemployment as the only criterion of impaired economic integration.

1.4.2 Epilepsy and job difficulties

"Simply knowing that someone has epilepsy, is not a very useful baseline from which to begin to assess an individual's employment prospects"
(p580, Craig & Oxley, 1988)

From a study on the psychosocial aspects of epilepsy (Chaplin et al., 1992), it was found that 70% of a community-based population of people with epilepsy were concerned about stigma and discrimination at work.

In order to learn more about these problems it is necessary to examine a working population. In a study of twenty-nine Occupational Physicians, MacIntyre (1982) found that, of the employees with epilepsy who were fully employed, one third had a job difficulty.

The term 'job difficulties' refers to problems encountered in getting work that matches the individual's abilities and qualifications. The literature suggests that people with epileptic seizures are undervalued by their employers because there is an over-representation of people with epilepsy in semi-skilled or unskilled occupations (Rodin et al., 1972).

The table below shows the percentage level of job difficulties found amongst people with epilepsy over the past 30 years.

Table 1.1 Job Difficulties

College of GPs	1960	26%
Pond & Bidwell	1960	44%
Lione	1961	76%
Jones	1965	62%
Porter	1968	34%
Elwes, Marshall, Beattie & Newman	1991	46%

This is further illustrated by Jones (1965), who conducted a twelve year study covering 39 cases of employees or prospective employees in an 'integrated steelworks' employing approximately 10,000 men and 400 women. He concluded that, of those people who were fully employed (33 out of 39), the two thirds who had had to change their

jobs "...were forced to accept more menial, less interesting, and less lucrative employment"(p488).

The problem of employment and epilepsy is therefore not just one of unemployment but must also include job difficulties as well. Very little is known about the problems of integrating within a workforce.

Most previous research has tended to concentrate on the characteristics of people who are unemployed. This, however, has not tended to produce findings which have improved the integration of people with epilepsy. The concentration on unemployment leads to the view that the core of the problem is within the individual and the only solution is more or better rehabilitation. However, directing attention towards the employed people with epilepsy gives us an opportunity to look at employment practice and suggest ways to improve the employment prospects of someone with epilepsy. By studying employed people, we have the opportunity to address the issue of economic integration from a different perspective to that of recruitment and thereby overcome some of the inadequacies in our knowledge that have led to the present employment problems of people with epilepsy.

It was pointed out by the British Epilepsy Association (BEA 1979) that the social acceptance and understanding of epilepsy has lagged behind the advances in medical treatment made over the last 50 years. This is also true for acceptance at work (Elwes et al., 1991). Despite the substantial literature about epilepsy and employment (Levine et al. 1988), which has largely been focused on the biomedical perspective (DeVillis & McEvoy DeVillis, 1986), progress towards an understanding of the issue is being impeded by the absence of a model which encompasses the diversity of the problem (Kielhofner, 1985; Dell, 1986; Zaiwalla, 1990).

This thesis will explore the reasons suggested for employment problems from a systems perspective. This will be achieved by taking a holistic approach to the problem area. The thesis will examine the issue from medical, social, psychological and occupational perspectives, and it will explore the evidence for these reasons from empirical research into the experiences of people with epilepsy at work. The aim is to formulate a systemic model which can lead to a greater understanding of the complexity of the problems faced by people with epilepsy at work and

to the identification of methods for positive intervention to improve the situation. The framework which will lead to the formulation of the model was developed from the literature and from the observations based on the preliminary study. The framework will be used to guide the literature review in the following way.

Chapter Two will examine a series of descriptions of epilepsy, in order to develop an integrated understanding of what is meant by the concept of epilepsy and to illustrate that epilepsy is more than just one thing and must be thought of as a complex construction of many variables.

Part Two of the thesis will critically analyse the literature on epilepsy and employment and examine concepts of relevance to employment. This will look at the medical issues (Chapter Three), the social/psychological issues (Chapter Four), the occupational/human factors issues (Chapter Five) and the legal issues (Chapter Six). An evaluation of the respective importance of these issues in predicting employment problems and a framework for the empirical work will be outlined in Chapter Seven.

Part Three will use the framework to explore the experiences of people employed in three organisations. In Part Four the data will be discussed in relation to the framework and emergent issues. This will then be evaluated for its usefulness in explaining the occurrence of employment problems for people with epilepsy. It will also be evaluated for its usefulness in identifying intervention strategies. This in turn will suggest where and how positive intervention strategies and future research can be made.

The objectives of this thesis are:

1. To analyse critically the literature on epilepsy and employment in order to determine the current state of knowledge about the problem.
2. To describe a framework for empirical analysis.
3. To survey working populations of people with epilepsy to determine the extent to which they are experiencing problems at work and the elements which most affect their situation.
4. To define the problems which employed people with epilepsy have with their employment.
5. To develop a model which helps to identify points of intervention to improve the employment situation for people with epilepsy.
6. To suggest possible intervention strategies and to suggest possible future research.

CHAPTER TWO

WHAT IS EPILEPSY?

Contents

2.0	Overview
2.1	The mythology of epilepsy
2.2	Epilepsy as a psychiatric diagnosis
2.3	A neurological description
2.4	A clinical description
2.4. 1	Causes of epilepsy
. 2	Timing of seizures
. 3	Warnings (auras) of a seizure
. 4	Remission rates
. 5	Age of onset of epilepsy
2.5	A pharmacological description
2.6	An epidemiological description
2.7	A psycho-social description
2.8	Summary and main points

2.0 Overview

In this chapter, a series of descriptions of epilepsy will be given. These are drawn from a number of disciplines, reflecting the diversity of the area. The objective of this chapter is to establish the background from which our understanding of epilepsy is formed. We will start with the history of epilepsy which illustrates where current misconceptions about epilepsy have their origin. I will look at neurological and medical descriptions of epilepsy and finally at the individual's view of epilepsy. Issues raised in this chapter will be further developed in Chapters 3, 4, 5 and 6.

2.1 The mythology of epilepsy

Epilepsy has always been a condition which has produced unfounded fears and prejudice. The earliest references to epilepsy are probably to be found in the code of Hammurabi, King of Babylon, 2000 BC. The code regulated the marriage of people with epilepsy and refuted the validity of their testimony in a court of law (Office of Health Economics, 1971). Perhaps it is not surprising that epilepsy has been feared by most societies throughout history, as there has been no obvious organic explanation of the disorder, and because of the sudden and sometimes ferocious nature of the seizures (Hill, 1981).

Without an obvious organic explanation, epilepsy was believed to be a sign of divine retribution and possession by spirits. Even the word 'epilepsy', which is derived from the Greek word meaning 'to take hold of', expresses the image of epilepsy as being possessed. It was thought that only a God could turn a sane man mad and then return his sanity (Hill, 1981). According to the Christian gospel, epilepsy was attributable to demons rather than Gods. Ross (1978) refers to a reference in the Bible which illustrates this. It is told by Mark (9 : 14-29), Matthew (17 : 14-21) and Luke (9 : 37-42). According to Mark's version,

a man brought his son to Jesus saying that he had been possessed by a demon since childhood. Jesus "...rebuked the foul spirit, saying unto him: Thou dumb and deaf spirit, I charge thee, come out of him, and enter no more into him. And the spirit cried, and rent him sore, and came out of him and he was as one dead; in so much as many said, He is dead. But Jesus took him by the hand, and lifted him up, and he arose" (The Bible, St Mark, Ch9, v.25-27). The cure for epilepsy then was to speak directly to the spirit or demon.

In ancient Greek literature another word was sometimes used instead of epilepsy which reflected another suspected non-organic cause for epilepsy and that was 'seleniazetai', which literally means 'is moonstruck' (Ross 1978). The word 'seleniasmos' is still used today in modern Greek to mean epilepsy.

Alongside these popular views, more scientific studies were also attempted. The earliest scientific study of epilepsy probably began in 400 BC. According to the medical theories of the time, epilepsy was attributable to one of the four humours. Hippocrates, in his book 'On the Sacred Disease', correctly identified epilepsy as a condition of the brain and not of possession.

Galen by 175 AD had distinguished between seizures originating in the brain without known cause (idiopathic) and seizures originating from diseases or other known causes (symptomatic), and had coined the term 'aura' to refer to the sensation which some people get prior to a seizure (Hopkins 1987). However, in line with the beliefs of the time, he still believed that seizures were influenced by the moon and that they were most likely to occur when the moon was full (Hill 1981).

Progress towards a better understanding of epilepsy did not develop quickly and by the late Middle Ages some fairly bizarre treatments were being suggested. Grant (1976) records the instructions given by Antonius Guainerius, a physician and lecturer in medicine at the University of Pavia in the early fifteenth century. Guainerius writes that in the care of a patient, "...if a paroxysm comes to an epileptic, let it be your aim to prevent the ascent of vapours, and as far as possible to draw the matter downwards. Therefore, perform vigorous rubbings or painful ligatures on the extremities, on the buttocks; under the knee make a slight incision with a cupping glass; and call the patient in a loud voice by his own name - Place a wooden peg

between his teeth - Also when an epileptic falls, at once kill a dog, and give the gall to the patient in any way that you can. If the one who first sees the attack urinates in his own shoe and then stirs it around as if to wash it, then gives the urine to the patient to drink, afterwards, the patient will be entirely delivered" (quoted by Grant (1976) p11).

The idea that epilepsy can be cured by doing something at the time of the seizure is still prevalent in some parts of the world today. Something similar to the above was practised in Nigeria up to the 1960s: cow's urine was "...poured into the mouth of the unconscious epileptic patient"(Dada, 1968). Another myth we have inherited is that epilepsy can be transmitted at the time of the seizure. Burden (1974) quotes a contemporary record of a sermon given by a Christian bishop which warns his parishioners to keep away from someone having a seizure because it was possible to catch epilepsy from their 'contaminated breath'.

These beliefs are often reflected in the stereotypic beliefs of people today. Superstition is still a phenomenon of our modern societies.

Even in the most advanced societies, epilepsy is still viewed with suspicion and fear by some people (Schien 1991).

2.2 Epilepsy as a psychiatric diagnosis

During the 17th and 18th centuries, epilepsy became the domain of the discipline of psychiatry. There was no effective treatment and therefore people with epilepsy were contained within the new mental asylums. At that time there were two views of mental illness, which were not fully developed until the mid-19th century (Hill 1981). One view was that mental disorders were discrete and numerous; this led to the classification of many different disease entities. A notable attempt to define a few main categories was made by Kraepelin towards the end of the 19th century. In the first edition of his textbook, epilepsy was categorised as a neurosis but in subsequent editions it was given a category of its own.

The alternative view of mental illness was that it was a unitary phenomenon, a single disorder with varying stages of severity. In this view, epilepsy was seen as a stage between neurotic symptoms and dementia. Epilepsy was a regressive phenomenon

resulting from a disinhibition of the higher centres of the brain. It was claimed by Lombroso (quoted by Hibbert 1963) that the link between moral imbecility and criminality was epilepsy. In France, a slightly different concept emerged: that of the degeneracy theory formulated by B. A. Morel in 1857. His theory was to prove highly influential and pervasive.

Within the degeneracy theory, epilepsy was hereditary and degenerative, progressively becoming more severe in each generation until idiocy wiped out the strain. Terms such as 'epileptic neurosis' came to be used to describe attacks of mania, extreme moral perversion or wilful viciousness, which were attributed in some people to a masked or undeveloped epilepsy. Henry Maudsley wrote that "...the epileptic neurosis is certainly most closely allied to the insane neurosis, and when it exists in its masked form, affecting the mind for some time before convulsions occur, it is hardly possible to distinguish it ..." (Maudsley 1873). This affirmation of the degeneracy theory led to its acceptance throughout the world. It is easy to see how the concept of particular personality traits in people with epilepsy ('the epileptic personality') took a firm hold within this

theoretical approach. Even as late as the 1950s, textbooks were still following Morel's degeneracy theory (Hill, 1981).

The consequences of this approach to epilepsy were twofold. Firstly, there has been an enormous stigma attached to having epilepsy. The person with epilepsy was seen as liable to insanity and unpredictable attacks of violence. Their only destiny being social, moral and intellectual degeneracy. The second consequence was that, as epilepsy was viewed as congenital and its effects inevitable, this meant that there was no attempt to investigate the possibilities of treatment in a scientific manner, as there was considered to be no hope of a cure.

In the 19th century, another approach towards epilepsy emerged, based on the detailed description of seizure phenomena and a physiological understanding of the nervous system. The early neurologists, principally Russell Reynolds and Ernest Gowers from the National Hospital for Nervous Diseases, Queens Square, did not accept Morel's theory. Hughlings Jackson was the first to describe what was happening in the brain by developing the concept of epilepsy as

being a sudden discharge of cerebral neurones and coined the term epileptiform or epileptoid (Hopkins 1987).

This led the way to our current understanding of epilepsy, but curiously it was the misconceptions about the origin of epilepsy which coincidentally produced the first real therapeutic breakthrough. In the 19th Century the cause of seizures was attributed to sexual excess, the treatment for which was potassium bromide. Aside from causing temporary impotence, potassium bromide was found to have anticonvulsant properties. The success of this treatment led to research which in turn led to the development of other anti-convulsant drugs which are still used today.

During this century, there has been the development of technology which has enabled neurologists to locate lesions in the brain associated with seizures and to study the electrical discharge of neurons across the cortex through the electroencephalogram (EEG). These major achievements have led to a better understanding of what happens during a seizure and have immeasurably improved the possibilities of

treatment and control of epilepsy. Epilepsy is no longer viewed by the medical profession as a psychiatric phenomenon.

2.3 A neurological description

Epilepsy is defined as a recurrent tendency towards seizures (Abbott, 1990). In neurological terms, a seizure is a 'paroxysmal discharge of cerebral neurons sufficient to cause clinically detectable events that are apparent either to the patient or to an observer' (Hopkins, 1987). This description excludes cerebral events related to the depression of neuronal activity in, for example, migraine; and excludes cerebral events related to the activity of spinal neurones such as spasms in paraplegia. However, it includes seizures which affect only particular areas of the brain, for instance the mesial temporal lobe or somatosensory area, where seizures are apparent only to the person experiencing them; it also includes seizures which are apparent only to the observer in cases where a seizure occurs during sleep.

Seizures can occur in all animals with a vertebrate nervous system. Marsden and Renolds state that "...the propensity for seizures increases in parallel with the phylogenetic scale, culminating in the highest incidence in humans" (p148, Marsden & Renolds, 1988). Generalised seizures can occur in all humans (electroconvulsive therapy demonstrates this); however, the threshold at which the activity in the brain results in a seizure will vary between people. Someone who has epilepsy may have a lower seizure threshold than other people. This low threshold may be due to genetic factors or a trauma in the brain. Stimulation of the brain's activity may be due to a combination of neurochemical and other metabolic processes which are going on all the time in the brain but which occasionally reach a particular level which is beyond the threshold and hence a seizure results.

2.4 A clinical description

In common clinical practice, an operational definition of epilepsy is based on clinical observation of behaviour. However, a precise clinical description of epilepsy is not easy to

achieve because there are many different causes of seizures and there are many different types of seizure. Hopkins (1987) makes this point thus:

"...epileptic seizures occur at any age, are of many different types, arise as a result of many different pathologies, have a variable genetic basis, may be precipitated by environmental events, and may start, or stop, for no clearly defined reason"(p1).

The common element is a sudden and abnormal electrical discharge in the brain but there is an almost infinite variety of epileptic attacks. Seizures can occur at any time of the day, start and stop at any age. It has been proposed that it would be better to refer to the 'epilepsies', rather than epilepsy, in order to reflect the variations in clinical manifestation (Espir, 1981).

A classification system has been developed to describe the various seizure types (ILAE, 1989). This indicates that seizures can be divided into two main groups, focal (partial) and generalised. Focal seizures are an abnormal electrical discharge which begins in or is focused on one area, or possibly a number of areas, in the brain. Depending on the focus it can be associated with any combination of sensory, motor, or psychic

experience. The discharge may spread slowly without loss of consciousness and without causing a convulsion. The most common form of focal epilepsy is centred in the temporal lobe.

Generalised seizures are characterised by an electrical discharge throughout the cerebral cortex of both cerebral hemispheres. This results in a sudden disturbance of consciousness. There are two manifestations, tonic-clonic (grand-mal) and absence seizures (petit mal). In absence seizures (petit mal), which are the commonest form of seizure among children, there is only a brief interruption of consciousness without convulsions. For an observer, the only discernible signs may be a pause in activity and a fluttering of eyelids. The most commonly recognised type of seizure among adolescents and adults is a tonic-clonic seizure and the one most people will associate with epilepsy. This is convulsive and is associated with complete loss of consciousness and balance. The individual will initially fall to the ground which will be followed by a series of spasms which may last several minutes. Recovery from this type of seizure will be gradual and may involve some mental confusion and possibly temporary loss of memory. The table overleaf describes in detail the classification of seizures.

Table 2.1 International seizure classification

1. Focal seizures (Partial)
 - A. Simple (consciousness not impaired)
 1. with motor symptoms,
 2. with special sensory symptoms, (e.g. buzzing)
 3. with autonomic symptoms,
 4. with psychic symptoms.
 - B. Complex (with impairment of consciousness)
 1. Developing impairment of consciousness, with:
 - a) no other features,
 - b) features as in (A) 1 - 4,
 - c) automatisms.
 2. Impaired consciousness at onset, with:
 - a) no other features,
 - b) features as in A. 1 - 4,
 - c) automatisms.
 - C. Partial seizures secondarily generalized.
 1. Simple partial evolving to Generalized Tonic-Clonic Seizures (GTC),
 2. Complex partial evolving to GTC,
 3. Simple partial evolving to Complex partial evolving to GTC.
2. Generalized seizures
 - A. 1. Absence seizures (Petit Mal)
2. Atypical absence seizures
 - B. Myoclonic seizures
 - C. Clonic seizures
 - D. Tonic seizures
 - E. Tonic-clonic seizures
 - F. Atonic seizures
3. Unclassified epileptic seizures

All seizures that cannot be classified due to inadequate or incomplete data. This includes some neonatal seizures, e.g. rhythmic eye movements, swimming movements.

(Table adapted from: The International League Against Epilepsy, Commission on Classification and Terminology. 1989)

Knowing the type of seizure and how these seizures affect the individual is important to the determination of employability.

2.4.1 Causes of epilepsy

No cause can be identified in most cases of epilepsy (Gering & Copping, 1980; EFA, 1987); these cases are referred to as 'idiopathic'. Where a cause can be identified, epilepsy is the result of abnormalities in or trauma to the brain; these are referred to as 'symptomatic'. The most common causes of symptomatic epilepsy are described as follows:

Table 2.2 Causes of epilepsy

1) Genetic factors	- increased susceptibility to symptomatic epilepsy.
2) Antenatal & birth factors	- eg. neonatal asphyxia and birth trauma leading to brain damage.
3) Infection of the nervous system	- eg. meningitis. Brain damage may be localised, as in a brain abscess, or diffuse, as in virus encephalitis.
4) Toxic factors	- eg. alcohol or lead poisoning.
5) Cerebral injury	- one of the primary causes
6) Ageing factors	- circulatory disturbances, neoplasms and degenerative diseases associated with ageing can be associated with brain lesions leading to late onset epilepsy.

2.4.2 Timing of seizures

Seizures can occur at any time of the day or night. Some people will have seizures only during sleep, others have seizures more regularly on waking. Some early research on this issue (inaccurately attributed by Hopkins & Garman (1987, p125) as Langdon-Down & Brain, 1929) has shown that there are also several peak times during the day for seizures to occur. For those people who tended to have seizures during sleep the peak times were about two hours after going to sleep and in the early morning. For those with a pattern of seizures occurring whilst awake the peak tended to be in the first hour after waking. Some evidence would suggest that the non-focal primary generalised tonic-clonic seizures are the most likely to occur during this period (Janz, 1962; Rodin et al, 1976).

2.4.3 Warnings (aura) of a seizure

Some people with epilepsy will report the experience of a warning or aura prior to a seizure. These auras can take different forms and are reported to occur at different lengths of time prior to the seizure. Some people will experience an aura regularly while in others they may occur only occasionally. Auras take different forms for different people depending on the location of the

seizure. For instance the aura of seizures in the temporal lobe may be associated with a rising "...epigastric sensation; a foul taste or smell; vertigo and auditory hallucinations; formed visual hallucinations; speech disturbance and autonomic phenomena" (p152 Marsden & Reynolds, 1988).

2.4.4 Remission rates

The College of General Practitioners (1960) estimated that there was only one chance in eight that a first seizure would be repeated and require continuous treatment. Studies conducted in the 1970s and 1980s indicated a good prognosis of between 40% and 68% of patients entering long-term remission. These have been followed in recent years by more contradictory findings. In 1990 two studies of patients following a first seizure showed widely different remission rates, 22% (Hart et al, 1990) and 71% (Hauser et al, 1990). An attempt to explain the disparity in these figures has been made by Chadwick (1991), who suggests that it may be partly due to Hauser's study including a large proportion of people (80%) receiving anticonvulsant medication as opposed to a much smaller proportion (15%) in the study by Hart. Evidence suggests that the use of anti-convulsants can reduce the risk of a second

seizure by 50% (Musicco 1989, reported in Chadwick 1991). Hart et al (1990) report that in the treated group the remission rate was 43% after 36 months. This is closer to the rates found in earlier studies, as is shown in the table overleaf.

Table 2.3 Patients seizure-free for at least
 two years at follow-up

	N		%
Zielinski(1974)	98	(field study)	42
Hauser & Kurland(1983)	516		40
Juul-Jensen & Foldspang (1983)	1024		44
Goodridge & Shorvon(1983)	100		68
Hart et al (1990)	564		22*
Hauser et al(1990)	208		71

* 43% of treated patients

There are several factors which affect the remission rate; these include the aetiology, age, time since first seizure and type of seizure. Remission is lowest for partial seizures (Zielinski 1988); idiopathic seizures; in people under 15 years or over 60 years, in the first weeks or months following the first seizure (Hopkins, 1987).

2.4.5 Age of onset of epilepsy

The age of onset for epilepsy can be at any time during an individual's life. The most frequent age of onset is in the first 10 years of life; about 30% of people with epilepsy have their first seizure during these years (Goodridge and Shorvon, 1983). About three quarters of people with epileptic seizures will have had their first seizure by the age of 30 years. There is then a decline in the number of people having their first seizure until the age of 60 years.

2.5 A pharmacological description

Drug treatment can prevent seizures occurring in "...the vast majority of individuals afflicted with epilepsy" (p233, Livingstone, 1970). About 80% of people with epilepsy should have their seizures satisfactorily controlled using medication (Lione, 1961).

Research at the beginning of this century led to the development of all the main first-line anti-convulsant drugs which are still used today. The pharmacological treatment of epilepsy has greatly improved over the past few decades. However, anticonvulsants work by a number of mechanisms, most of which are largely unknown

(Shorvon, 1987). This means that it is still not possible to be precise about which drug will be best for which pattern of seizures. The following oral anticonvulsants are the most commonly used.

Table 2.4 Oral anticonvulsants

Carbamazepine*	(Tegretol)
Clonazepam	(Rivotril)
Ethosuximide	(Zarontin, Emeside)
Phenobarbitone	(Luminal)
Phenytoin*	(Epanutin, Dilantin)
Primidone	(Mysoline)
Sodium valproate*	(Epilim, Depakin)
(trade names in brackets)	

The three anticonvulsants marked '*' are first-line drugs.

There are occasionally drawbacks to the use of some anti-convulsants. There are toxic effects of all the above drugs if the dosage in the blood stream exceeds the therapeutic level. These issues will be discussed in greater depth in section 3.10.

2.6 An epidemiological description

In deciding how many people have epilepsy, we must first agree on a definition of epilepsy (Schaumann et al., 1990). As we have seen from the clinical description, there are many types of seizures. Additional definitional difficulties arise because there is no agreement about when an individual stops having epilepsy. For instance if the individual has only had one seizure or not had a seizure for many years, can this still be defined as epilepsy? Epidemiological studies have failed to arrive at a consistent definition of epilepsy and this is one reason why there is some confusion as to how many people can be said to have epilepsy. In overall terms, there are two categories of definition found in the epidemiological studies. These can be described as a narrow definition, covering only active epilepsy and a broad definition, which includes anyone who has ever had a seizure. For instance Pond et al. (1960) defined epilepsy as the occurrence of a seizure in the previous two years or currently taking long-term anticonvulsant medication (a narrow definition); whereas Brewis et al. (1961) applied the term to anyone who had experienced more than one definite epileptic attack (a broad definition).

To determine the size of the population with epilepsy, it is necessary to establish both incidence and prevalence rates for the condition. Both methods have their problems. The incidence rate of epilepsy refers to the number of new cases occurring during any given period of time and within a specific population. The establishment of incidence rates generally requires a longitudinal prospective survey; because this survey method is time-consuming and expensive, the number of studies looking at incidence rates is smaller than the number of studies looking at prevalence.

The prevalence rate of epilepsy is the measurement of the proportion of the study population who have epilepsy at the time of a study. Generally, prevalence rates will refer to individuals with active epilepsy. The problem with prevalence is expressed by the Office of Health Economics in their pamphlet 'Epilepsy in Society' (1971) thus:

"...recorded prevalence levels for epilepsy, in common with any other condition, are largely dependent on the definition of the condition and on the proportion of cases likely to be made known to the inquiring agency. Before the second war, and in the immediate post-war years, estimates of the number of people with epilepsy were based on data from hospitals. Because hospital doctors do not see all patients with epilepsy, the estimates tended to be on the low side." (Office of Health Economics 1971 P8).

For epilepsy, the proportion of a population likely to be hiding or denying their condition is high, therefore, figures derived from prevalence studies must include a (possibly large) error figure.

Studies conducted using these two types of definition are listed in the two tables below. It can be seen that the prevalence and incidence rates overlap between narrow and broad definitions. This would seem to indicate the ambiguity of the categories described here. Each study has a different methodology and this produces different results. The only study which identifies the definitional problems and uses several different definitions is that of Goodridge and Shorvon (1983), which is included in both the narrow and broad categories.

Table 2.5 Broad definition of epilepsy

STUDY	PREVALENCE (RATE PER 1,000 POPULATION)	INCIDENCE
Logan and Cushion. 1958	3.3	---
Lione 1961	6.0	---
Brewis et al. 1966	5.5	0.3
Goodridge & Shorvon 1983	20.3a	---
	17.5b	---
Key	a) excluding febrile seizures	
	b) excluding single seizures	

Table 2.6 Narrow band definition

STUDY	(RATE PER 1,000 PREVALENCE	POPULATION) INCIDENCE
Pond, Bidwell (1960)	6.2	0.7
College of Practitioners(1961)	4.2a 0.6b	0.6 ---
Hauser & Kurland (1975)	0.7	---
Hopkins and Scambler (1977)	0.3c	---
Goodridge & Shorvon (1983)	10.5d	---
" "	5.3e	---

Key a) people with chronic epilepsy
 b) first seizure
 c) people over 16 years old
 d) uncontrolled and controlled seizures
 e) uncontrolled seizures only

The Goodridge and Shorvon (1983) study, drawing its data from a general practice base, found that 20.3/1000 people had sustained at least one non-febrile seizure. This means that, over the whole population, there are 2% or approximately one million people in the UK who have had an isolated seizure at some time during their lifetime, most commonly in childhood. About ten people in 1000 will have more than one seizure and develop chronic epilepsy (taking anticonvulsant medication for most of their lives i.e. the narrow definition), making a probable total of 500,000 people with active epilepsy out of the 50 million people in the UK.

In order to identify how many people with epilepsy might be in employment, we can say that about a third of the population will be of employable age. Therefore, about 167,000 people with epilepsy will be in the labour market or could join the labour market. Given this calculation, even if the most conservative figures are taken, epilepsy is the most common neurological condition found in a working age population.

2.7 A psycho-social description

An attempt at creating a method of measuring the psychological and social dysfunction of someone with epilepsy has led to a different type of definition of epilepsy. This is based on the construction of psycho-social inventories. The advantage of this approach is to widen the definition of epilepsy to include aspects which had previously been ignored. Until 1980 there had not been an inventory specifically designed to look at the particular concerns of people with epilepsy. This was rectified by Dodrill et al (1980) who produced the Washington Psycho-Social

Inventory which is composed of the following seven areas:

- Family background
- Emotional adjustment
- Interpersonal adjustment
- Vocational adjustment
- Financial status
- Adjustment to seizures
- Medicine and medical management

These areas were identified as important from the literature and from clinical experience. An extension of this methodology was adopted within the National General Practice Survey of Epilepsy (NGPSE) in the U.K.. Here the areas of psycho-social concern were identified from interviews with people who had epilepsy and are based directly upon descriptions provided by people with epilepsy (Chaplin et al 1990). Several of the areas are the same but the list is more comprehensive. The findings from the preliminary investigation revealed the following twenty-one areas to relate to the individual's experience of epilepsy as shown overleaf.

Table 2.6 Psycho-social areas affected by epilepsy

Attitude towards accepting the seizures
Attitude to the label 'epilepsy'
Fear of having seizures
Fear of stigma in employment
Lack of confidence about the future
Concern about performance at work
Concern about sexual relationships
Concern about platonic relationships
Concern about housing
Lack of confidence about travelling
Adverse reaction on social life
Adverse reaction on leisure pursuits
Change of outlook on life/self
Difficulty in communicating with the
family
Problems with taking medication
Distrust of the medical profession
Misconception about epilepsy
Depression or emotional reactions
Feelings of increased social isolation
Lethargy/lack of energy
Sleep disturbance

This type of approach helps to identify what definition people with epilepsy are using. It has been stated elsewhere that rarely have people with epilepsy been asked what it is like to live with the condition and deal with its consequences (Schneider & Conrad, 1983); the move towards the development of psycho-social inventories like those above are beginning to provide an answer (Hermann & Whitman, 1986; Kirchagassler, 1990; Hermann, 1992).

The NGPSE study showed that for the person with epilepsy, their experience of epilepsy can be seen as a set of problems. The major problems are firstly, the fear of the next attack and, secondly, fear of stigma in employment (Chaplin et al, 1992).

This chapter has demonstrated that epilepsy is a common condition which is not one thing but has many manifestations. Unfortunately the popular view is that epilepsy is always characterised by tonic-clonic seizures.

From ancient times, epilepsy was seen as evidence of possession by devils and some of the mythology associated with these beliefs may live on in the current stereotype of epilepsy. Epilepsy was also associated with mental illness and this idea has lived on in popular culture and has contributed to the social labelling of people with epilepsy as being strange and different from the rest of the population, with unpredictable behaviour and odd personality traits. The chapter has outlined the current medical understanding of the condition as a function of neuronal activity unrelated to personality factors.

An attempt to look at the experiences of the individual has been undertaken in the form of a social and psychological description of epilepsy. This has resulted in an accumulation of different descriptions about how epilepsy affects quality of life. A very positive outcome of this is that it has opened the way to identify what epilepsy is

from the perspective of the person with epilepsy. Research so far has indicated the importance of employment for the person with epilepsy. Fear of stigma in employment was judged as the second most important concern to people with epilepsy, following anxiety about having seizures.

It will be appreciated that epilepsy is not one thing; it is an historical, neurological, clinical, pharmacological, historical, social/psychological phenomenon which defies precise description because its mechanisms and consequences remain largely unknown.

Main points

- 1 There is a mythology attached to epilepsy which has created a stereotypic image of the person with epilepsy.
- 2 The view that epilepsy is a psychiatric phenomena is historically derived and incorrect.
3. Epilepsy is the occurrence or susceptibility to have seizures. Seizures are a neurological event that can occur in all vertebrate animals.
4. There are many different types of seizure with a wide range of symptoms.
5. About 80% of people can have their seizures satisfactorily controlled with medication.
6. Side effects are possible with all types of anti-convulsants.
7. Epilepsy is the most common neurological condition found in a working population.
8. Epilepsy can affect a wide range of psychological and social aspects of a person's life. The main areas of concern are anxiety about having seizures and fear of stigma in employment.

PART 2

LITERATURE REVIEW

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CHAPTER THREE

MEDICAL ISSUES

Contents

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3.0 Overview

This chapter will explore and evaluate the medical issues that have been suggested in the literature as reasons why, or factors in the equation for, the existence of employment problems. These will be evaluated from the perspective of their contribution towards a greater understanding of the problem of employment.

There are several medical variables which need to be examined, and we will deal with each of these in turn. Where possible, a distinction will be made between effects on unemployment and effects

on work performance. This chapter will also identify issues which we might expect to affect employability but which have not been adequately explored in the literature.

3.1 The frequency of seizures

The influence of seizure frequency has been considered by some researchers to be very important and has been rejected by others. It is an issue which has been looked at in isolation, and viewed as a single-factor predictor of problems.

3.1.1 Seizure frequency and unemployment

Seizures are the most obvious demonstration of the fact that a person has epilepsy. However, there is disagreement about the role that it plays in unemployment. Some researchers claim a strong relationship between seizure frequency and employment (Dennerll et al, 1968; Rodin et al, 1972; Sillanpaa, 1977; Scambler & Hopkins, 1980; Thorbecke & Janz, 1984), whereas others claim that a direct relationship between frequency of seizures and gaining or maintaining employment is unfounded (Walker, 1957; Gorden & Russell, 1958; Goodglass et al, 1965; Porter, 1968; Juul-Jensen,

1961; Fraser, 1981). Let us take a closer look at some of these studies. Firstly, I will examine the evidence for no difference.

Walker (1957) found that, of people with post-traumatic epilepsy, 50% of those who were seizure free were unemployed and there was 59% unemployment amongst those with continuing attacks. Gordon & Russell (1958) also found that amongst the employed there were people with very frequent seizures, sometimes more than that found in the unemployed group. This view is backed up by Porter (1968), who found that within a group of eighteen patients with the most frequent seizures (more than one per month) there were "...eight [who] fell into the unemployable group, five who had sporadic difficulty with employment, but it is interesting to note that five had had no employment problems" (p84). Frequency of seizures alone, therefore, would appear not to be a bar to gainful employment. Fraser (1981) points out that it is possible to accommodate even relatively frequent seizures in specific jobs. Juul-Jensen (1961) states that, in most of the cases of unemployment, the inability to get a job was due to other factors than seizure frequency, such as: loss of driving licence, emotional disturbance; fatigue due to drug regimen, low intelligence and

other disabilities or diseases. Thomas (1948) states that it is not possible to determine employability purely on frequency or severity of seizures; a better determinant would be the number of times a person has been badly placed in a job and the number of times they have been dismissed.

Zielinski (1984) observed that employment rates for people with epilepsy and for the general population were no different, both in the USA and in Poland. He pointed out that differences referred to in the literature related to the method of formulating the study populations (case series) from specialised centres. "...the opinion that epileptic seizures are of more importance for employability is usually based on two fractions of a case series: those with epilepsy associated with other incapacitating disorders (neurological, intellectual, or behavioural) and those in whom seizures are considered as the only problem"(p578). Thus he believes that, where differences are observed, these are due to other causes and not due to the seizures. He states that this aspect of epilepsy and employment has never been properly explored and therefore judgement must wait till further research is done.

Turning to the claim that there is a relationship between seizure frequency and unemployment, Rodin et al. (1972) have defended this claim but stated that the relationship is being hidden by the methodology used to examine it. They give the following example from their own study of 114 males with epilepsy who had completed their education. They showed that there was a significant difference between employment and unemployment depending on whether the subject had had less than one seizure in the previous year or not. However, when the same data were broken down into more categories the "...effect is diluted and the differences do not average as statistically significant" (p151). The tables below, reproduced from Rodin et al (1972), illustrate this.

Figure 3.1

Table (a) from Rodin et al 1972 (p 151)
114 males with completed education

Seizure frequency	Employed	Unemployed
Less than once a year	21	5
Once a year or more	<u>41</u>	<u>47</u>
Total	62	52

$X^2 = 9.45$
 $P < 0.01$

Table (b) from Rodin et al 1972 (p 151)
114 males with completed education

Seizure frequency	Employed	Unemployed
Less than once a year	21	5
About once a year	3	3
2-3 a year	4	9
4-6 a year	5	7
7-12 a year	4	3
Once a month	5	4
2-3 a month	10	5
Once a week	0	3
Several a week	<u>10</u>	<u>12</u>
Total	62	52\$

t = 1.68, not significant. \$\$

NOTE

\$ The total figure in the unemployed column is quoted as in the original, however, the total is 51 not 52.

\$\$ The use of the t-test leaves open the question of whether the comparison is actually between parametric and non-parametric data rather than how the data is divided.

Rodin's objection therefore is legitimate (although the data he gives do not necessarily prove this, see note) and, as he states, "...it does seem rather strange" (p151) that seizure frequency is not important.

The experience of someone who acts as a vocational evaluator for people with epilepsy is reported by de Boer (1984), who records examples of people who have lost their jobs due to frequency of seizures. She suggests another possible reason why there is

a difficulty in the literature over this point, namely that the type of epilepsy is not included in these studies.

The current situation is that the claim of no difference appears to be founded on studies with methodological anomalies, but the claim that seizure frequency does make a difference is also unproven because studies showing this have not taken sufficient notice of confounding variables.

3.1.2 Seizure frequency and work performance

Only one study has related seizure frequency to work performance (based on sickness absence, accidents and performance ratings by the supervisor) and that was by Udel (1960). He looked at a working population of people with epilepsy and found that the occurrence of seizures did affect work performance. His data show that "...two-thirds of the cases rated equal to or better than their own work groups were in good control [of their seizures]; whereas, only 4 of the 12 cases rated below their own groups had achieved control" (p262). Udel is careful to conclude that overall "...the group of epileptics studied are capable of normal work performance" (p263), although he also points out that the sample is too small and has an inherent bias due

to case selection "...so that it is not possible to make the same claim for all epileptics" (p263). It is difficult to say what should be concluded from this except that more research needs to be done. However, picking up the criticism from the previous section we can see from Udel's work that he too fails to give an account of the other difficulties this group has.

3.2 An increase in frequency

A different problem to seizure frequency per se is the effect of an increase in seizure frequency. This is a factor overlooked by all the previous studies mentioned and yet could be one contribution to the reason for apparently contradictory findings. Only one study has looked at this (Janz, 1972). Janz examined the effects of an increase in seizures by looking at 'social mobility'. Within a population of 400 people with epilepsy, in the course of four to twelve years, 8 per cent of the subjects experienced a fall in employment status. He was not able to identify frequency of seizures as a significant variable. However, looking at the group which deteriorated he found that 80 per cent had experienced an increase in their seizures. He concludes that the critical variable may be the increase in seizures not the actual frequency of the seizures.

and generalised seizures. There is, therefore, no evidence that any single seizure type is directly related to unemployment but some evidence that a mixture of seizure types may have an effect on employment.

3.3.2 Seizure type and work performance

After the person with epilepsy has gained employment, there is still no indication that having any one type of seizure will predict a difference to the person's work performance. Gorden and Russell (1958) examined the medical records of 400 patients with epilepsy attending the National Hospital for Nervous Diseases. They found that the type of seizure was not related to the employment grade of the person with epilepsy. Walker (1957) also found that 'work habits' did not correlate with neurological status and Udel (1960) noted that "...the aetiology or type of epilepsy did not influence performance"(p262). None of these studies indicated effects of mixed seizure patterns, but this was not an element which was looked at specifically.

3.4 Events triggering a seizure

Certain events may trigger the occurrence of a seizure and where these events occur at work we may presume that they may affect employability. If triggering events can be identified then it may be possible to avoid these in a work situation.

However, there has never been a rigorous study of possible triggering events at work. The reason for this may be that in most cases seizures cannot be attributed to events in this way. It has been noted that the identification of, and validity of, these attributions are sometimes based on the flimsiest of correlational evidence (Hopkins, 1987).

The most predicable factor in triggering seizures is non-compliance with the drug regimen. There is, however, some evidence for the role of the factors shown in Table 3.2 in seizure precipitation.

As you can see from the table, the triggering events most likely to occur as a result of work are either reflex causes, such as flickering VDUs, or stress. Both of these areas will be dealt with in detail in the next chapter.

Table 3.2 Suggested seizure triggers

Deprivation of sleep

Menstrual cycle

Toxic and metabolic causes

 Acute alcohol intoxication

 Withdrawal from alcohol

 Hypoglycaemia

 Hypoxia

Reflex causes

 glare, flashing lights, television, VDUs

 reading, sounds, being startled

Stressful life events

(Table taken from Hopkins, 1987 p124)

3.5 Timing of a seizure

Time of day of attacks could play a major part in the employability of an individual, as seizures occur less frequently during working hours than at other times (Hopkins & Gorman, 1987). This implies that it is possible for someone with uncontrolled, even possibly frequent, seizures to maintain a job without having a seizure at work. According to the driving regulations in the UK, it is accepted that if someone has only had seizures during sleep for the previous three years then they are very unlikely to have them while awake and can be considered safe to have a driving licence. There is again a lack of research on the effects of the timing of seizures on employability or job difficulties.

3.6 Recovery time after a seizure

The length of time taken to recover from a seizure can make a difference to performance because, the longer the time taken to recover, the greater disruption in the workplace (Fraser, 1981). It has also been pointed out that some people are embarrassed or angered by a seizure, while others may quickly readjust and resume work straight away. Other individuals will be so fatigued they will take a day off to recover. It would be reasonable to assume that recovery time is a critical factor in work performance / sickness absence, but, there is very limited evidence to indicate this and no replication of the observation by Fraser (1981) quoted above.

3.7 Warnings (aura) of a seizure

Where the aura is dependable and gives sufficient warning, the possibility of avoiding embarrassment for the person with epilepsy is greatly increased and it clearly could be an important factor in permitting some people to retain employment and maintain work performance (Goodglass et al 1963). However, what work has been done on auras in relation to unemployment has suggested that, amongst the unemployed, auras "...did not occur significantly" more often (p110; Gorden & Russell 1958) than was found in the employed subjects. The

limited research on this would seem to indicate that the fact of having a warning may not help in getting a job but it may help in keeping a job once employed.

3.8 The effects of other disorders

The major piece of quantitative evidence presented on this issue was given by Rodin et al (1977) who stated that the major handicapping factor to getting a job is not the epilepsy but the level of impaired "...neurologic and psychologic performance"(sic) (p38). In their study, Rodin et al. identified 369 people with a definite diagnosis of epilepsy, which meant at least three seizures. 23 per cent of these subjects had epilepsy only, as opposed to the others who had associated intellectual disturbances, neurological handicaps or behavioural problems. Rodin et al. found that the "...epilepsy-only group functions very much like one would expect of the general population, without being appreciably handicapped in school or work performance by their seizures" (p35). Udel (1960) was able to examine his sample of 77 people with epilepsy from 4 companies in terms of work performance associated to "...neurological, psychiatric, or cardiovascular impairments"(p260). He concluded, rather ambiguously, that "...the presence of a defect did

not appear to influence the performance rating ... However, in the absence of a defect, more epileptics were scored equal or above (average) by a factor of five" (p261). The table below was quoted in the study. If a Chi Square test is performed on this table it can be shown quite clearly that the presence of a defect does make a significant difference ($X^2 = 7.35$, $p = <0.01$) to the judgement of work performance.

Table 3.4 Work Performance

	Defect	No Defect	Total
Equal or above	13	39	52
Below	13	8	21
Total	26	47	73

The defects which are most likely to be associated with poor employment records have been observed to be low intelligence (Porter, 1968; Walker, 1957; Rader et al., 1978) and personality disorders (Porter, 1968). McLellan (1968) would agree that epilepsy is not the primary cause of problems. He concluded that: "...epilepsy is sometimes a symptom of organic brain disease and the other features of such diseases are frequently much more significant for employment than the epilepsy itself"(p9).

All standard anti-convulsants can have side-effects at certain dosages and for certain individuals; these side effects could affect employment. The possible side effects for some of the common anti-convulsant drugs are shown in the overleaf.

Table 3.4 Aniticonvulsant side effects

<u>Generic (Trade) Name</u>	<u>Most common side effects</u>	<u>Most common toxic signs and symptoms</u>
Phenobar- bitone (Luminal)	Sedation, paradoxical excitement, rash, irritability & hyperactivity, especially in children	Drowsiness, ataxia, nystagmus, slurred speech.
Phenytoin (Dilantin)	Skin eruptions, hyperplasia, coarsening of facial features, decreased blood folate level, hypocalcemia, hepatitis, hypertichosis, fever	Nystagmus, ataxia, slurred speech, drowsiness, diplopia blurred vision
Primidone (Mysoline)	Same as Phenobarbitone.	Same as Phenobarbitone.
Ethosuxi- mide (Zarontin)	Nausea, skin rash, blood dyscrasias drowsiness, hiccups	Nausea, vomiting, anorexia, lethargy, headache, hiccups.
Carbamaze- pine (Tegretol)	Nausea, vomiting, blood dyscrasias, anorexia.	Vertigo, drowsiness nystagmus, diplopia unsteadiness.
Clonazepam (Rivotril)	Sedation, drowsiness ataxia, behavioural problems, anorexia.	Somnolence, confusion, coma, hypotension.
Valproic acid (Depakene)	Nausea, vomiting, drowsiness, weight transient alopecia, hypersalivation.	Ataxia, sedation.

Any of these may lead to a reduction in effectiveness at work or to social or psychological problems. The question has been raised by some researchers as to whether the side effects of anticonvulsants affect the ability to obtain and hold a job (Blank & Anderson, 1983). Efficiency is believed to be seriously impaired by an inappropriate drug regimen and therefore must be considered as a variable in explanations of employment problems.

Some side-effects will be easy to detect but changes to a person's character may be more subtle where, for instance, the speed of the individual's mental processes are reduced. This may happen in such a way that the individual barely notices it themselves. The possibility that the side effects of drugs are causing difficulties should always be raised where the efficiency or work performance of an individual is questioned (Edwards 1974). Pederson (1987) quotes Schultz & Thorbecke (1984) stating that the dosage of anticonvulsant drugs was the most important factor in slowing the subject's work pace.

The people who are most likely to experience side effects of anti-convulsants are those whose seizures are the most difficult to control and who are taking the highest doses of anticonvulsants (McLellan 1986).

3.10 Age of onset of epilepsy

Assuming that most people begin their working lives at about 17 years of age, we can expect that approximately 40% of the people with epilepsy will have their first seizure after that point. Epilepsy beginning during employment is therefore a significant possibility. Curiously this is not an issue which has been dealt with in the literature. However, onset prior to starting working life can also affect later employability.

It is thought by some researchers that the earlier the age of onset, the more likely it is that there will be serious consequences on psychopathology (Mittan 1986) and hence greater effect on later employment (Dominian et al., 1963; Fukuyama et al., 1963). Harrison and Taylor (1976) showed a depressed occupational achievement rate for people with an early age of onset and continuing seizures. In their study, 200 people with epilepsy were followed up over a 25 year period with the age ascertainment between the first day of life

and the 14th year. Using this series it was possible to contrast people whose epilepsy was in remission with those who had continuing epilepsy. They found that there was a much depressed occupational achievement amongst the people with continuing epilepsy. People with continuing epilepsy were "...under-represented, compared to the group as a whole, in the higher occupational categories - that is, professional, managerial, skilled clerical jobs, and over-represented in the lower occupational categories" (p950). There would appear to be clear evidence from this study that chronic epilepsy with an onset prior to age 14 years results in underemployment.

We have seen that many medical factors have been investigated as single factor explanations for employment problems. It has, however, been difficult to find where these factors can demonstrate a statistically supported effect. Evidence for the effect of seizure frequency on employment is confounded by a number of methodological problems. These problems include the statistical method chosen, the composition of the population studied and the effects of confounding variables. There would seem to be evidence that:

1. An increasing seizure frequency can be used as a predictor of employment problems.
2. Mixed seizure types are also indicated as having a greater effect on unemployment than any single type of seizure, although seizure type has not been shown to affect work performance.
3. There are methodological anomalies which might be obscuring real effects in some studies showing no effects of the medical condition on employability. The procedure of using a large number of categories in frequency tables has been demonstrated to obscure a real significant relationship.

4. No research has been done on the triggering effects of events in the work place or the effects of time of day of seizures on work performance.
5. The presence of an aura is suggested to be more important to keeping a job than to getting a job.
6. There is quantitative evidence to suggest that the presence of other disorders affects work performance more than epilepsy itself does. Most studies in this area are based on observation and they implicate intelligence and personality as having greater effect on work performance than epilepsy.
7. There is also the observation that recovery time after a seizure could affect work performance.
8. Medication side effects are heavily implicated as reducing efficiency at work.
9. Early onset of epilepsy may affect childhood development with consequent long term effects on employability.
10. Onset during employment is not an issue which has been dealt with by the literature and yet could seriously affect employment.

CHAPTER FOUR
PSYCHO-SOCIAL ISSUES

Contents

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4.0 Overview

This chapter will look at the psycho-social reasons for someone with epilepsy having employment problems. It is often difficult to disentangle the psychological from the social and therefore they will be covered together in this chapter. The concept of learned helplessness as a model of the psychological effects of seizures will be examined and the evidence for the effects of stress on the precipitation of seizures will be reviewed. Finally we shall look at more social aspects including consideration of Goffman's

populations. This biased selection of subjects tended to include a high incidence of people with personality disorders, partly due to the effects of institutionalisation and partly because people with personality problems are more likely to be institutionalised.

Despite Tizard's widely known and critically supported review, reference to personality differences persisted in the literature for over a decade. Examples can be found in Hauck, (1968, 1972); Moya et al, (1968); and Vinson, (1975). In effect there has been no evidence for an epileptic personality but the concept may persist in the public mind. We may find a reason for this by looking at the reasons proposed for an effect on personality. We shall look firstly at the experience of having the label 'epilepsy' and then at the experience of having seizures.

4.2 Experience of having the label 'epilepsy'

In addition to the seizures, the person with epilepsy also has to cope with other people's attitudes towards them as someone with epilepsy. These attitudes may become apparent from casual remarks and from behaviour towards the individual. Brimacombe (1985) gives an account of a boy of 15

years who has epilepsy and has to deal with the fear of his classmates. He did not know what a seizure looked like until he witnessed someone else having one in the cinema: "...everyone panicked, some started screaming. Now John is more ashamed than ever of his condition; he will take anything to stop the seizures" (p203). When epilepsy becomes viewed as stigmatising, "...people quickly learn to regard the status of 'epileptic' as a social liability" (p57; Scambler, 1989) and the fear of enacted stigma predominates in their minds.

For someone who develops epilepsy, psychological adaptations which are at first seen as temporary may, through reinforcement, become normal patterns of behaviour (McHugh, 1991). Ordinarily, when we become ill, we have little difficulty in integrating our sick role with our normal interpersonal relationships. However, when the condition is chronic, this integration has to become permanent, which can seriously distort interpersonal communication (Arntson et al, 1986; Scambler & Hopkins, 1986; Schaefer & Fenwick, 1987). This adjustment to what has become or is perceived as a 'handicap' may lead in general

terms to a reduction in the overall quality of life with a loss of opportunities for personal development.

For someone who has epilepsy from birth or develops epilepsy at an early age, the effects of the social and medical aspects of epilepsy can have a profound effect upon psychological development (Graham, 1958; Arntson et al, 1986). A personality problem that already exists may be amplified because of the social response to the epilepsy (Goodglass 1963).

4.3 Overprotection

The loss of control over one's life, through control being taken away by others, is likely to have effects upon the individual's personality and personal development (Schultz & Decker 1982; Wallston et al 1983). For instance if the parent's view of epilepsy is that it is something to be ashamed of, the child may learn this view and withdraw from social interaction (Schneider & Conrad, 1980) thus affecting their personal development. The individual may feel less confident and have lower expectations in terms of work and general achievements (Dell, 1986).

Results from Greenspan and Shoultz (1981) suggest that social competency is the critical factor in the job tenure of people with disabilities generally. It would seem that, given the likelihood of an over-protected environment, the chances of developing appropriate social skills may be limited. It is therefore possible that people with epilepsy may find that, like other people with disabilities, it is a lack of social competence which stops them from getting or keeping a job.

4.4 Disrupted education

Early age of onset of epilepsy may affect employment through the disruption of schooling. One of the most comprehensive studies of childhood and epilepsy has been the National Child Developmental Study (NCDS). At age 11 years it was found that 67 per cent of children with epilepsy were attending normal schools. However, Ross and West (1978) found that at 11 years, children with epilepsy attending ordinary school scored below controls on academic subjects. Children with epilepsy were also found to be twice as likely to be absent from school, 13 per cent having missed at least one month in their eleventh year compared to 6 per cent of controls. At fifteen years, the

percentage of children with epilepsy attending ordinary schools dropped to 58%. Other studies have shown that the reading ages of children with epilepsy are lower than controls by up to 12 months (Rutter et al 1970; Ross et al 1980) and that poor progress was widespread (Holdsworth & Whitmore 1974).

Such studies may be criticised for their case series inclusion which do not identify subjects with other medical conditions in addition to the epilepsy. Again we must try to disentangle the effects of epilepsy on its own from that of low intelligence, behavioural disturbance and so on. Sillanpaa (1977), from an epidemiological and prognostic study of childhood epilepsy in South Western Finland, has similar findings to those we might predict from the above studies. He finds that the child with epilepsy is only 25 per cent as likely as the general population to gain qualifications beyond the compulsory school level. However, he also points out that his sample includes subjects who have persistent seizures and this is "...most commonly related to brain damage and associated intelligence defect, as is the case in the present series" (p33). Therefore, we cannot expect this group to perform as well as the general population.

4.5 The experience of having seizures

A more clearly psychological explanation for personality differences is given by Dell (1986) who, in talking about fear of seizures, stated that: "...one can only imagine how it would feel to be confronted, for example, by the daily fear of dying suddenly somewhere from a seizure. It would in the very least seem reasonable to conclude that these social and psychological stresses might affect the individual's ability to function in society"(p196). One consequence of this is the denial of opportunities, perhaps because of legitimate concerns about ability, which leads to beliefs about not being good enough to do new things (Bagley, 1972) and not having high expectations of what can be achieved (Walker, 1982). Here we will find the theory of learned helplessness useful to explain the mechanism of personality change (Dell, 1986).

Learned helplessness was first described by Seligman (1975), who showed that if an animal was faced with a stressful and random situation over which it had no control, the animal would eventually resign itself to its fate and endure the stress, with subsequent stress-related physiological damage. The experiment Seligman carried out to demonstrate this involved placing a

dog in a cage which had two compartments separated by a barrier. A mild electric shock was delivered through the floor of one side of the cage or the other. If the shock was preceded by a light going on, the dog would quickly learn to jump the barrier and thus avoid the shock when it was applied. If the light was not used (and therefore the shocks were unpredictable) the physiological strain was shown to be very high, with the dogs eventually giving up all normal activity; in effect, they learned helplessness.

Similar responses were shown to occur in humans (Thornton & Jacobs, 1971) when loud noises were used as the stressor. It has also been shown that helplessness in one situation can be transferred to reactions in other situations (Hiroto & Seligman, 1975). It has been concluded that uncontrollable and unavoidable stressful events of any sort may impair any organism's ability to cope with subsequent problems (Hiroto & Seligman, 1975).

It is very easy to see how this concept might apply to someone with epilepsy. Seizures are often uncontrollable and unavoidable stressful events and the experience of these may well induce the feeling of helplessness in people. Some authors

have speculated that the evidence of learned helplessness can be found where people with epilepsy have been characterised by underachievement (Milne, 1974), poor attention span (Stores et al., 1978), non-competitiveness (Goldin & Margolin, 1975), and social isolation (Mellor et al., 1974).

Although the application of the concept of learned helplessness is very plausibly applied to the effect of seizures, there is no evidence that seizures do result in learned helplessness. It would be impossible to control for all the confounding variables. For one thing, during a tonic-clonic seizure, the person with epilepsy is unconscious and may be unaware afterwards that they have had a seizure. What effect does that have on producing learned helplessness?

As was pointed out by Lefcourt (1973), merely possessing the illusion, if not the reality, of control over one's circumstances reduces the negative psychological and emotional effects of potentially stressful situations. As we will see in Chapter Five, people with epilepsy will often cite stress as the cause of their seizures; perhaps whether this is actually the cause or not does not matter to the feeling of (potential)

control that this may bring. The individual's view of epilepsy and how they deal with seizures need not agree with any scientific perspective except their own, for if the illusion of control exists then there is still a beneficial effect (Ferreira, 1963) and thereby no learned helplessness.

We can say, that given that it is not possible to identify a specific epileptic personality, it is still possible to say that epilepsy is likely to have an impact on the individual's personality. This effect, however, may be manifested in different ways in different people. It therefore makes sense to talk about external rather than internal causes. Let us now look at stigma as an external cause of employment problems for people with epilepsy.

"Resistance to the employment of epileptics is due less to the objective physical handicap of the seizures than to the attitude of society" (p322; Goodglass et al 1963).

It has often been argued that the roots of the problem with employment is the intense social stigma to which people with epilepsy are subjected (e.g. Goldin & Margolin 1975; Lennox & Lennox 1960). Wright in 1976 echoes this same point: "...perhaps the most serious barrier to rehabilitation, and one with which all persons labelled epileptic must cope, is public fear and stigma. In fact, for many people with epilepsy, society's attitude is more devastating than the disorder itself"(p493, Wright, 1976). According to this view the 'social attitude' which applies to people with epilepsy would apply to all people with epilepsy regardless of type or frequency of seizures.

Perhaps the best known work on stigma was done by Goffman in 1979. He said that the central feature of the stigmatised individual's life can be stated thus: "...it is a question of what is often, if vaguely, called 'acceptance'. Those who have dealings with him [the stigmatised person] fail to accord him the respect and regard which the

un-contaminated aspects of his social identity have led them to anticipate extending, and have led him to anticipate receiving; he echoes this denial by finding that some of his own attributes warrant it"(p19 Goffman 1979). Goffman states that society initiates the context in which stigma can thrive by telling the individual that they are both normal and yet different, and that to deny this would be foolish. For a stigma to exist, society must have a collective image of a difference between a discernable group of people and the rest of society. That difference must be non-trivial and, for the stigma to become effective, the individuals within the group must believe that they are discreditable. Below we will explore Goffman's idea of stigma in relation to epilepsy.

4.7 The function of a social label

The social definition of epilepsy is composed of the label which society puts upon those who have the condition and the way it treats them. Human beings are strongly disposed towards the use of labels and categories in order to explain their environment (Lindesmith et al, 1977). A series of beliefs about an object or group of people, come together to form a label (Tajfel, 1980). These labels are fairly stable and serve the function of

generalise, due to the "...ease with which public opinion tends to transform exceptions into generalities" (p621, Beaussart-Defaye, 1984).

In a review of studies, Stevens (1975) noted 57 attributes ranging from 'adhesive' to 'wilful', all of which were supposed to relate to people with epilepsy. These generalisations have developed into a powerful body of lay 'belief' which is difficult to change (Schneider & Conrad 1980). Epilepsy therefore tends to be associated with fear, horror and superstition (Visnon, 1975) which are essentially medieval misconceptions (Espir 1981) and with aggression and crime (Bagley, 1972).

These beliefs survive because "...they are emotively satisfying to the individuals who express them"(p37 Bagely, 1972). Such theories remain in place until an alternative theory can be postulated. However, as Stevens observes, "...a bold and plausible theory that fills a scientific need is seldom broken by the impact of contrary facts and arguments"(p153, Stevens, 1957). The image applied to people with epilepsy constitutes a bold theory which fills the need of people to

understand epilepsy. In the next section we will look for proof that the image has become a popularly held belief.

4.9 The collective image of epilepsy

In order to determine whether a collective image exists, researchers have turned to public attitude surveys. The paper most quoted in this regard is by Caveness and Gallup in 1980, in which they reported the result of 30 years of recording trends in the views and feelings of the public about people with epilepsy. The questions asked included:

"Would you object to having any of your children in school or at play associate with persons who sometimes had seizures (fits)?"

"Do you think epilepsy is a form of insanity or not?"

"Do you think epileptics should be employed in jobs like other people?"

The surveys were conducted on large samples of the United States population between the years 1949 and 1979. The results showed that attitudes were fairly equivocal towards people with epilepsy in 1949 (57 per cent of the sample would not object to their children playing with someone with epilepsy; 59 per cent thought epilepsy was not a form of insanity; 35 per cent thought people with

epilepsy should not be employed like other people) but that in 1979 attitudes significantly improved (89 per cent had no objection to their children playing with children with epilepsy; 92 per cent said epilepsy was not a form of insanity; 9 per cent thought people with epilepsy should not be employed in jobs like other people).

However, this survey has been criticised for its simplistic view of attitude measurement. Schneider and Conrad (1983) indicate that the pressure on people to express socially acceptable attitudes about disability is stronger now than it was in 1949; therefore, the people answering Caveness & Gallup's questions may not actually believe in their statements and would possibly not be prepared to act on them.

An alternative approach to the social survey was adopted by Hansson and Duffield (1976), who used an established experimental procedure in which subjects are asked to judge the characteristics of people for whom they only have photographs. The photographs are categorised into attractive and unattractive people; previous research has shown that an unattractive person will be attributed with more negative characteristics than an attractive person. The overwhelming finding was

that subjects attributed epilepsy to the unattractive people. The ease which subjects "...leaped into relating attractiveness and epilepsy is dramatic" (p238; Hansson and Duffield, 1976).

We have, therefore, established that there is a stereotypic and extreme view of epilepsy, we have also established that the image is generally held in society. What we now need to know is whether this difference matters. In other words, are people with epilepsy discriminated against because of epilepsy?

4.10 Does the difference matter?

A good demonstration of an actual case where discrimination can be shown is related by Porter (1968), who took 100 random cases of epilepsy drawn from his neurological clinic at Central Middlesex Hospital and examined their medical and employment backgrounds. Of these, there were some who were subsequently discovered not to have epilepsy. He makes the interesting observation that there was one case of a man who had suffered an anxiety attack and had been labelled 'epileptic' "...when he had recovered from his anxiety state he could not be placed in work and

he had been attending the Labour Exchange for 9 months. When I saw him he was very well and the reason for his anxiety had resolved itself. The label of epilepsy was removed and he has been satisfactorily employed ever since" (p87).

Another example that the image matters is provided by Floyd (1986), who reported that the colleagues of a young woman with epilepsy employed in an accountant's office became "...unnecessarily concerned about their own involvement" (p5) in dealing with her seizures.

This confusion about epilepsy leads to a general fear of epilepsy. Fear has been explained in two ways. Firstly, as a psychodynamic reaction in which fear is generated by the recognition of one's own unconscious impulses: "...the basis of .. prejudice is hypothetically that of fear, fear of the sudden loss of physical and emotional control"(p37, Bagely, 1972). The direct observation or the knowledge that people with epilepsy can lose control of themselves makes us realise that we too are capable of such behaviour and because we are frightened of what we might do, we try to hide from our own self-knowledge by rejecting the person with epilepsy and declaring that they are not like us, 'not normal'. The fear

of the unpredictable has been applied not only to epilepsy but also to the prejudice against black people (Hill, 1981), homosexuals and people who break the incest taboo (Freud, 1905). This explanation of fear then is based on the anticipated consequences of a breakdown in the usual social constraints, either in emotional, behavioural or sexual terms.

A second explanation of fear is again an internal process but based on the fear of a person's inadequacies. As Brimacombe (1985) points out, it is people's ignorance that frightens them. When they see a seizure it is difficult to believe that, as a mother of a teenager with epilepsy said, "...anything so violent and energetic as a grand mal seizure can be totally harmless"(p203). Brimacombe also reports a description of a seizure given by a non-medical observer who said "Nobody knows what to do but there is nothing to do. Epilepsy emasculates the observer; you just have to wait until the seizure subsides." If it is the sight of a seizure which makes people feel powerless and inadequate and if this is something to be fearful of, then to avoid a situation where they might have to confront a seizure they must

avoid people with epilepsy. The fear is transferred from their own inadequacies to the people with epilepsy.

Therefore, it appears that people act upon their beliefs in the collective concept of epilepsy; the difference between the image of people with epilepsy and the reality does matter. However, Goffman says that this is not enough; for stigma to exist, the person with epilepsy must also believe in this collective concept and believe that it is right that they should be stigmatised.

4.11 Acceptance of stigma

It has been found that people who feel socially handicapped by their epilepsy have more difficulty in getting work and possibly have a higher unemployment rate than those who do not feel handicapped (Gerstle de Pasquet E. et al, 1984) Those people who believe in the stigma can become preoccupied with feelings of stigmatization and these feelings are then internalised (Ryan et al. 1980), thus eventually leading to behavioural anomalies (Bagley, 1972). It has been observed that "...the prejudice and rejection which are often encountered may cause as much distress as the epilepsy itself"(p32) (Espir, 1981). Once the stigma has been internalised, substantial barriers

leading to a normal life - especially employment - are created (Mittan et al. 1983). Fear of stigma in employment is one of the largest problems reported by people with recent onset of epilepsy (Chaplin et al, 1992).

The acceptance of stigma is the internalisation of the prejudice of others taking on society's image of epilepsy and seeing themselves as that stereotype. For the individual, this results in the development of a pessimistic outlook on life and a reduction in self-esteem (Goffman 1979). We cannot know for sure the impact that harbouring the fear of stigma has on a person with epilepsy. It would seem likely that the social and psychological stresses of believing that he or she will be stigmatised will affect the individual's ability to function in society.

Goffman observes that "...persons who have a particular stigma tend to have similar learning experiences regarding their plight, and similar changes in conception of self - a similar 'moral career' that is both cause and effect of commitment to a similar sequence of personal adjustments. One phase of this socialization process is that through which the stigmatized person learns and incorporates the stand-point of

the normal, acquiring thereby the identity beliefs of the wider society and a general idea of what it would be like to possess a particular stigma" (p45). MacIntyre quotes Disabled Resettlement Officers as remarking that, once people with epilepsy are dismissed because of seizures, they "...began to feel like ex-convicts do, and tended to develop personality problems" (p203). People with epilepsy therefore, will tend to view themselves in the same way that the outside world views them.

One of the major reasons for problems with employment then is the poor self-image of the person with epilepsy (Benson, 1977). The result of the experience of epilepsy or perception of stigma may be to lower the self-esteem of the individual. Several studies have shown that lowered self-esteem of the person with epilepsy affects lifestyle and ability to cope with their world (e.g. Taveira et al, 1990).

4.12 Is stigma inevitable?

From the above description of stigma it is easy to assume that everyone with epilepsy is highly stigmatised and that the consequences are unavoidable. However, as with previous analysis, it is a mistake to forget that the individual is

(Kaplan et al. 1977; McLeroy et al., 1984) and acts as a buffer to stress (Wilcox, 1981). It is seen as having both a direct positive effect on health status and serving as "...a buffer or modifier of the effects of psychosocial and physical stress on the mental and physical health of the individual" (Broadhead et al, 1983). From the discussion above we can see that social support may be very helpful in giving an alternative view of the self to the individual than the one provided by society. Social support may therefore mean that the individual does not have to accept that the stigmatised view applies to them or that the stigma matters.

4.14 Concealment

Scambler (1984) suggests that concealment increases the person with epilepsy's feelings of stigmatisation and will lead to personal anguish and unhappiness. An empirical investigation of the effect of concealing epilepsy is of course impossible because if it were possible to identify the study population then they have clearly not been successful in concealing their epilepsy. The effects of concealment can, therefore, only be subjected to conjecture. However, concealment

cannot be rejected as a possible confounding variable when examining the effect of stigma on the individual.

4.15 Summary and main points

It has been proposed that epilepsy does not necessarily result in a distinct personality type but that the effects of sudden and unpredictable seizures and the experience of growing up and living with the stigma of epilepsy may affect the personal development and behaviour of people with epilepsy.

The arguments for an effect are very convincing. The application of psychological theory (learned helplessness) and sociological theory (Goffman's theory of stigma) reinforce the view that epilepsy should have a significant impact on the lives of people with the condition.

However, the discussion here has also emphasised that the psychological and social consequences of epilepsy are moderated by other variables such as social support, non-acceptance of the diagnosis, perceptions of control over the seizures. We have seen that these elements may counteract the adverse effects and therefore it is not possible

to predict the impact of epilepsy on any one individual without taking into consideration a much wider set of variables than has so far been considered.

The main points drawn from this chapter are:

1. It cannot be proven that there are personality differences between people with epilepsy and people without epilepsy. However, evidence for belief in personality change can be found in the literature.
2. Growing up with epilepsy and living with other people's views of epilepsy is thought to have a significant effect on personal development.
3. The person with epilepsy may be overprotected, which could have a negative effect on personal development.
4. Early onset of epilepsy could hinder educational achievement and thereby employability.
5. It is thought that the experience of having seizures must be devastating to the individual and could affect personality development.
6. In explaining the effects of epilepsy, not enough attention is paid to the positive influence of some aspects of the individual's life in counteracting the negative aspects of epilepsy.

7. Stigma is thought by some researchers to be the greatest problem for people with epilepsy.
8. A social label which serves a psychological purpose is easy to apply and hard to remove.
9. There is a collective and negative image of epilepsy which is based on myth and characterised by the view that epilepsy always takes the form of tonic-clonic seizures.
10. Stigma can be demonstrated to occur.
11. Fear of epilepsy may be based on either an emotional reaction to loss of control or based on fear of ignorance.
12. Observational evidence can be found that people with epilepsy do view themselves as 'epileptic' and that this creates a stigma which could lead to personality problems.
13. However, despite the existence of stigma, not everyone suffers from this to the same extent. Social support may reduce the feelings of stigma, whereas concealment may increase these feelings.

CHAPTER FIVE
OCCUPATIONAL ISSUES

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5.0 Overview

This chapter will explore occupational and human factors issues related to the employment of people with epilepsy. These issues constitute many of the dependent variables in regard to employment problems of people with epilepsy. Here we shall look at the advice available to management, the organisation of the work and aspects of work performance. This chapter will consider hazardous occupations, restrictions on use of equipment and accidents.

5.1 Organisational culture

The culture of an organisation is likely to reflect the values of the society and the views of the people in the organisation (Perrow, 1961; Mintsberg, 1979; Payne, 1987; Williams et al. 1989). As such, the culture will determine the way epilepsy is viewed. Let us look at what we know about the employer's beliefs about epilepsy. We are told that the average employer believes that the person with epilepsy represents absenteeism, on-the-job injury, and loss of company property (i.e. damage) (Lione, 1961); that they cannot be relied upon in times of special difficulty (Lindsey, 1982); that they will cause frequent accidents for which the employer will be liable; that seizures will stimulate anxiety in co-workers (Udel, 1960); and that accidents will lead to increased insurance rates (Lennox & Markham, 1953). To what extent this view is accepted will determine the approach and attitude of the organisation to someone with epilepsy. Let us look in more detail at the beliefs of employers.

McLellan (1986) describes the following findings of a survey of employer's beliefs of epilepsy:

- 34% believed a single attack constituted a diagnosis of epilepsy.

- 33% thought that less than 75% of people with epilepsy could achieve good control of seizures and lead normal lives.
- 30% believed that more than 50% of people with epilepsy had attacks more frequently than once a month.
- 43% believed that a doctor should be called even when consciousness was returning.
- 76% believed that people with epilepsy should not be allowed to work with heavy machinery even if they had a driving licence.
- 43% believed that insurance companies would insist on increasing their rates if people with epilepsy were employed.
- The frequency of epilepsy in the general population tended to be under-estimated.

The result of these beliefs is that where companies are willing to employ people with epilepsy, the majority of employers will only employ people who have fully-controlled epilepsy and then only in jobs which would be considered non-dangerous (Risch, 1962; Aspinall, 1984). Therefore, within any analysis of the employment prospects of someone with epilepsy, we must first consider the culture and knowledge of the

organisations to which they are applying. Let us now look at examples of advice from two areas where these beliefs and knowledge may originate.

5.2 Employment advice

This section looks at advice in the literature on the employment of people with epilepsy. A principle reason for restricted employment is that advice available to management does not take enough account of the variations in the condition of epilepsy as this quotation illustrates:

"Individuals whose epilepsy is controlled by medication are employable in a wide range of occupations... The kinds of jobs for which people with epilepsy are not suitable are those involving open flame, heights, machinery with large moving parts, or any circumstances in which, should a seizure occur, serious injury (or death) could result. For some individuals, loud unexpected noises may trigger seizures"(p 8-9, Gering 1980).

Despite the claim that there is a wide range of occupations for the person with epilepsy it is implied that even people with a long remission of seizures will not be able to obtain a job which might involve any hazards. Because this statement is not qualified by a definition of epilepsy, it applies (putatively) to everyone who might be called 'epileptic'. This would include people who have not had a seizure for years, people who might

not have had a seizure since childhood, people who only have seizures in their sleep, people who have a normal driving licence and people who have very mild seizures without loss of consciousness.

Another example is taken by Lennox and Cobb (1942), who are even more proscriptive in their approach. They look at the choice of job from the viewpoint of the physician. They believe that the jobs which are not suitable for people with epilepsy fall into three classes:

"First are occupations categorically forbidden because the lives of others might be endangered. These include the operation of fast moving vehicles, aeroplanes, automobiles, locomotives, elevators, street cars, or buses; positions of intense personal responsibility, major surgery, private duty nursing, trapeze performer, solitary watchman or lookout, swimming instructor, etc."

"Second is the operation of machinery of such a nature, or work at such a height, that temporary loss of consciousness might injure the patient or damage the machine; these occupations include house painting, bricklaying, carpentry, bridge building, steeple-jacking, mining, welding, machine tool operations, etc."

"Third are prohibitions which arise from popular reactions and prejudices. In this group, a controlling factor is the number of eyes focused on the person. The stage, the concert platform, or the pulpit is a more vulnerable position than a desk or counter. Nevertheless, we have had as patients, ministers, college professors, public school teachers, legislators, and bankers." (p574, Lennox & Cobb; 1942).

Porter in 1968 also made general proscriptions about jobs that people with epilepsy should not do and stated that people with epilepsy who are attending university ought to be guided away from certain subjects eg. science, technology and medicine, and towards administrative work eg. accountancy, some forms of legal work, social science and library work. These two studies take an approach based on the type of jobs which cannot be done by a person with epilepsy. This is of course a negative approach in terms of human resource management because it focuses on the exclusion of people in order to avoid difficulties. The alternative approach is to focus on the abilities of the individual in relation to the work and seek to find solutions to difficulties by adjusting the tasks to be done instead of adjusting the work-force.

A more positive approach is to look at the design of the work (Lawler et al., 1973; O'Brian, 1986) this view was taken by Goodglass et al. (1963) who stated that "...the critical factor in employment for the moderately severe epileptic seems to be the availability of a sufficiently tolerant work situation"(p337). They also state that the most successful placement for people with severe epilepsy is "...largely in situations where the

individual has understanding working companions and where some loss of time on the job does not destroy his usefulness or make him an economic liability"(p338).

Unfortunately, advice still often includes a list of prohibited jobs (Floyd et al. 1988). This list is often taken as the final word on career exploration. However, it should be remembered that lists of jobs that should not be done are not hard and fast rules which are legislatively laid down like driving requirements, but are guidelines. Lennox and Cobb (1942) have an extensive list of prohibited jobs but at the end of their paper they say "...in all cases advice must be fitted to the individual"(p574). It is on this maxim that modern occupational advice is often built.

5.3 Type of work

There has been very little work done in this area but if we look at Udel's study (1960) of what jobs people are actually doing, we find that people with epilepsy are doing skilled jobs in industry: "...eighteen of the 31 Clinic cases performed skilled work. In the Industrial group, 46 (61 per cent) worked at jobs requiring skill. This evidence indicates that epileptics are not as a group mentally inferior"(p263; Udel, 1960). In

modern industry, there is no reason why the person with mild epilepsy cannot be employed with safety ensured for himself and others (Whitty, 1968).

Employment problems for the individual result from either a lack of information-seeking or the information-seeking failing to result in management being able to place someone with epilepsy appropriately. This is a human resource management issue and a problem exists because management does not have the requisite amount of information or skill to control the situation adequately. Attempts to acquire that information are made more complex by managers being unable to express their information needs to medical advisors. The advice given (or the interpretation of the advice given) results in general guidelines and blanket restrictions. Such advice does not allow the manager the flexibility required to respond at a level appropriate to the needs of the situation.

Given this scenario, it is predicted from the law of requisite variety (Ashby, 1964) that the management must seek to resolve the situation by matching its skills to the demands of the management problem. This can be achieved in two ways: either increase the knowledge, skill and

flexibility of management or decrease the demand by not employing the person with epilepsy. Thus if high unemployment or lack of career progression is found amongst people with epilepsy, it would suggest that the second alternative is being chosen. A methodology for the analysis of this situation in organisations may be found in the application of the Viable Systems Model (Beer, 1979, 1981, 1985). Beer established a set of principles which govern organisations and permit the development of mechanisms for effective control and communication. This approach has been used to explain why people with epilepsy have difficulty in gaining employment (Chaplin, 1993).

5.4 Professional associations advice

Another major barrier to the employment of someone with epilepsy and the cause of many employment problems is inappropriate professional advice.

There are many instances where inappropriate advice or inadequate advice is given and, because it has the backing of a professional body, it will be given undue credence. For instance, in 1983 the International Labour Office produced an Encyclopaedia of Occupational Health and Safety (ILO 1983) in which it states that:-

'Work requiring exposure to heat, noise, radiation or glare, etc., work requiring rapid reactions or distribution of attention to several matters at the same time (e.g. despatch, control desk work, conveyer work) or work necessitating permanent contact with a large number of people should not be entrusted to epileptics'.

Additionally there are a number of employment-based Union regulations which limit employment by not qualifying statements on restrictions. Thus, it has been pointed out (Craig & Oxley, 1988) that a number of Unions advise that a person with epilepsy should not work near machinery, without making any reference to the type of epilepsy and conditions of the workplace that could constitute the hazard.

Let us now look at some specific organisational issues which managers will consider in relation to epilepsy.

5.5 Seizures in the work place

5.5.1 Stress and seizures

As was reported in Chapter Three, stress is recognised as a possible trigger of seizures. However, as is also reported, the attribution of a triggering event or factor is sometimes based on 'flimsy' correlational evidence (Hopkins, 1983).

Despite this, some of the literature on epilepsy and employment is very clear on what role stress in the work-place is expected to play in the generation of seizures. Gloag (1985i), in a summary of papers on employment delivered to an Occupational Health conference in London, concluded that stress in the work-place was considered an important factor by many physicians. McLellan (1986) points out that "...people who are very keen to prove themselves in their jobs and to make a good impression may put themselves under the kind of stress that makes seizures more likely to occur, and run into trouble for that reason"(p5). This is especially likely to occur during the first few weeks of a job when people are not sure of what is required of them. Seizures during this period would be particularly harmful to the establishment of relationships with co-workers and managers.

In contrast to this, Lennox & Cobb (1942) believed that stress may actually reduce the chance of a seizure rather than increase it. This has not been easy to demonstrate and some of Lennox and Cobb's ideas are based on an observation study carried out in England between 1940 to 1941, when bombing in the vicinity of institutions for people with severe epilepsy was seen as an example of extreme

stress and therefore likely to produce an increase in seizures (Shafor, 1941). However, "...contrary to expectation there has been no increase of fits" (p631, Tylor Fox, 1941).

On the other hand it is equally difficult to find evidence of a direct effect. This may be because the correlation between stress and seizures may not actually be directly causal. Espir and Rose (1987) point out that high levels of stress can lead to an increase in alcohol consumption, which may have an effect on the condition and the medication controlling the seizures. The result may be an increase of seizures due to the reduced efficacy of the medication and not due to stress directly. Effects upon medication could also explain McLellan's point above, if there is change in a person's routine, as when starting a new job, there is an increased chance of forgetting medication and hence an increase in the likelihood of a seizure.

The view that stress causes seizures would appear to be held by many people with epilepsy themselves. Mittan (1986) reports that possibly the greatest barrier to employment is the worry that job stress would precipitate seizures: "...in excess of 80% of our patients harboured this

concern"(p105). Mittan reported that many of the people in his sample had a fear of death, of brain damage, and of harm from industrial accidents caused by job stress leading to seizures. They told him that the risks to their safety and their mental health was not worth the money they might earn: "...fear that job stress would precipitate seizures was one of the more common explanations our patients gave for their failure to maintain employment."(p105) This fear resulted in people with epilepsy quitting jobs even when the economy was making it difficult to get any alternative employment.

Stress, then, may be an indirect cause of seizures in some people but the belief that it is causally associated with seizures may be a greater source of employment problems than the seizures themselves.

5.5.2 Physical effort and seizures

The association of stress and seizures has meant that employers have tended to rationalize their unwillingness to hire people with epilepsy by suggesting that the stress of hard work is likely to precipitate a seizure. Lennox & Cobb (1942)

attribute this view to "...a conception fostered by misguided medical opinion which overemphasizes the value of a stagnant existence" (p571).

In contrast to the common view, Fraser (1981) states that clinical experience suggests that physical involvement reduces the probability of a seizure. This is also supported by the similar finding of Kuijer (1978), who showed that seizures occurred during relaxation rather than during exercise.

5.5.3 Shift work and seizures

Adaptation to shift work is something which has been suggested will affect people with epilepsy, increasing the chances of a seizure. Shift work alone may cause persistent fatigue, sleep disturbance and other symptoms (Reinberg et al, 1983), this may be sufficient to reduce the effectiveness of the medication, but added to this, there is the additional problem of the lack of routine leading to people forgetting to take medication. Medical advice against shift-work is commonly given and, therefore, it is not surprising that there are significantly fewer people with epilepsy doing shift work (Dasgupta et al, 1982).

Difficulties with seizure control are believed to be particularly pronounced when shifts change (Brown, 1985). Switching from one sleep pattern to another is never easy, and "...shortage of sleep and fatigue may temporarily lower the seizure threshold. For this reason, shift work for which the timing of the shifts changes frequently is unsuitable for certain individuals"(p5, McLellan 1986). The normal drug regimen may also be disturbed and serum levels will therefore be difficult to maintain; this is especially true for drugs with a short half life such as Sodium

Valproate which may have to be taken up to four times a day (Brown, 1985). Methods do not currently exist to predetermine if someone with epilepsy will be tolerant of shift-work. It is only from the experience of working shifts that it is possible to tell someone's capability.

5.5.4 Disruption to work due to seizures

In order to maintain employment, Aspinall (1984) makes the point that seizures need not be fully controlled but that they should not occur at work. Hicks and Hicks (1978) observe that employers' attitudes towards seizures at work has improved: "...the consequence of an on-job seizure have changed... the modal consequence of an on-job seizure was dismissal in 1956; reallocation in 1966; and to require medical treatment in 1977" (p182). Many studies have reported surprisingly high numbers of people having seizures at work. Lennox and Markham (1953) reported that, "...of 140 persons, 89 (63 per cent) had experienced seizures while at work"(p1694). MacIntyre (1982), in a survey of 29 occupational physicians, found that, of employees with disclosed epilepsy, 65 per cent had experienced seizures at work, although "...61 per cent had less than one attack [at work]

per year"(p102). If a seizure does occur, there are three factors which affect the level of disruption caused: firstly, the severity of the attack; secondly the suddenness of the attack; and thirdly, the location and time of the attack.

A major seizure at work is likely to cause a great deal of disturbance and be a disruption to the work of others (Lindsey 1982). However, minor seizures may cause little disturbance or may not even be noticed (Aston 1964). Possibly the most disruptive seizures are those which occur without any warning of their approach, or occur in someone who was not known to have epilepsy (McLellan 1986). However, seizures may have minimal effects on working output where a short break can be easily made up (Aston 1964).

The unpredictability of a seizure can be the most worrying aspect, not only affecting the individual having the seizure but also work colleagues (Gloag, 1985ii). Employers may also feel that, as the seizure cannot be predicted, it could happen anywhere and hence it could happen at the most hazardous or inopportune moment. The unpredictable nature of the seizure means that the most disadvantageous circumstances are illustrated as a possible event.

5.6 Work Performance and epilepsy

Obtaining data on productivity is difficult for two reasons: firstly, there is no agreed definition of productivity and therefore no agreed method of testing it (Latham & Fry, 1988); secondly, to obtain data on the effects of epilepsy, comparisons are required between a person with epilepsy and a person without epilepsy doing the same job. This is difficult because people with epilepsy may be restricted in their employment and will therefore be under-represented in many jobs. This having been said, there have been a number of attempts to look at the work-performance of people with epilepsy. These studies are far from conclusive; some research appears to indicate that people with epilepsy are not able to offer the same level of work performance as people without epilepsy (Walker, 1957; Wilson, 1960), but there is more recent evidence for no difference in work performance (MacIntyre 1976; Benson 1989; Craig & Oxley, 1988; Dasgupta et al 1982).

In looking at these studies, we must be wary of the definition of work performance that is being used. Typically, performance is measured by attendance, punctuality, or hours on the job. These are perhaps not the best measures of performance but an objective measure of productivity, say, number of trees cut down, or cars sold, would be very difficult to obtain for most employees.

In the following sub-sections we will consider the evidence for some difference and no difference in performance.

5.6.1 Some difference in productivity

The evidence for some difference comes from a handful of studies. Goodglass et al. (1963) is the main source for evidence of a difference. In their paper they quote studies which indicate 'relatively poor work records' for people with epilepsy, including Ryther & Ordway (1918), Walker (1957), and Wilson et al. (1960). However, if these studies are examined they are found to be biased by factors influencing sample selection. For instance, in the Walker (1957) study, subjects were drawn from a population of people with post-traumatic epilepsy, and in the Wilson et al. (1960) study, subjects were drawn from a

hospital-based population. It would be quite wrong to draw generalised conclusions from these studies but unfortunately Goodglass et al. (1963) do not refer to the sample selection for the studies they quote.

An independent area of evidence for some difference in work performance comes from conclusions based on neurological studies. Dodrill (1978) argues, from the neurological evidence, that people with epilepsy will have reduced performance ability because there will be some brain deterioration due to the seizures. He is careful to say that when cognitive tests are applied there is no demonstrable evidence but that 'logically' there must be a deterioration and therefore the difference cannot be shown by the instruments that we currently have.

The evidence for some difference in work performance is therefore based on studies which cannot be generalised to the whole population of people with epilepsy and on conclusions drawn from the view that the occurrence of a seizure must impair long term functioning, despite a lack of evidence to support this position.

5.6.2 No difference in productivity

In general, reviews of the literature have tended to disregard the above evidence and state that there is no problem in terms of work performance for people with epilepsy. For instance, McLellan (1986) states that "...evidence seems to imply that people with epilepsy are better workers and take less time off" (p8); Craig (1988) also states that there are "...very positive findings about the performance of people with epilepsy in the workplace in comparison with workmates without epilepsy"(p580); Gloag (1985ii) reported that the work capacity of those who have epilepsy uncomplicated by other problems is good.

However, there are several different definitions of work-performance being used; in some cases performance means sickness absence and in others it means loss of time due to accidents. In very few studies is work performance defined in terms of work rate and quality of work, a definition more likely to be preferred by management. Gloag, for instance, quotes four references for her statement that work capacity is good, none of

which actually refer to work performance, these are:

<u>Reference</u>	<u>Measure used</u>
Udel, 1960	- lost time due to accidents;
OHE, 1971	- sickness absence;
Rodin et al, 1977	- psychological evaluations;
Hicks and Hicks 1978	- accident rates.

However, studies which do examine work performance can be found. Descriptions from a single company are often the best source of material because it is easier to control for variables and match with non-disabled people doing the same job. Lorbeer & Barron (1958) studied 63 employees with epilepsy at Lockheed. In their paper it states that "...in our experience, for the most part, epileptic employees under adequate medical control perform as effectively as the majority of other employees. We have found no unusual incidence of mental deterioration or reduced cerebral capacity. To the contrary, several important positions are being capably filled by epileptic persons"(p165).

In the study by Dasgupta et al (1982) of epilepsy in the British Steel Corporation, 45 people with epilepsy were found who were working in an industry employing 24,000 people. No differences

between people with epilepsy and people without epilepsy were found in respect of work performance scores.

Evidence from sheltered workshops employing people with epilepsy also show good work performance ratings. In a study by Sorel (1971), a workshop run by the Friends of the Belgium National League employed people with epilepsy exclusively. In describing the workshop it was stated that good work records were demonstrated but that people worked more slowly. The increased precision due to slower working speeds was said to be suited to the job they were doing which was electrical work. At the Epi-Hab workshop in the US a similar story was found: "Some 475,000 man-hours of work were subcontracted to Epi-Hab by industry. Only 425 man-hours have been lost because of seizures, roughly one hour for every 1,000 hours worked".

A comprehensive study of work performance was conducted by the United States Department of Labor in 1977. This was a statistical study comparing differences between the work performance statistics. People with epilepsy were matched to an unimpaired group and to other groups with different disabilities. The criteria for performance was overall production rates. The

study concluded that people with epilepsy perform as well as matched unimpaired workers in the manufacturing industries.

5.6.3 Critique of work performance literature

It is tempting to leave the analysis there and conclude that there is no difference in work performance. However, we must be careful due to the methodological difficulties expressed at the outset. Having criticised the studies showing a difference in work performance, now let us take a closer look at how the studies showing no difference were conducted.

In the study by Sorel (1971), good work performance results were obtained but if we look at the treatment given to the subjects we find that they were a very special group for three reasons:

- 1) many of the subjects had been followed by the clinic for 10 years, and therefore may have had the benefit of closer medical management than other people with epilepsy;
- 2) 70% were skilled labourers or professionals (for example, architects, cabinet-makers, electricians, masons), the majority having received their training after the epilepsy started;

3) social workers were heavily involved in the care of this group: "...the social worker encouraged [them] to take medication regularly, accompanied [them] to the doctor's office, helped [them] accept [their] handicap and encouraged [them] to continue working" (p59). In addition, the social worker informed the family, colleagues, and employers about the epilepsy and "...by sensible interpretation the social worker often made it possible for the patient to stay in his job"(p59).

In other words, this group is receiving a great deal of attention and it is also worth noting that the method of assessment used by Sorel states that work performance is divided into four categories: Excellent, Good, Left for other reasons, Fired due to "...fits or personality difficulties". Therefore, anyone who is working must be graded as good or above.

The increased attention would also be true for Epi-Hab, which is concerned to show that people with epilepsy can perform well and also possibly true for Lockheed. It is therefore worth repeating the point made by Hicks and Hicks (1978) that employers who are able to identify their employees

who have epilepsy may also be more concerned with the welfare of those people, thus increasing the chances of promoting good work performance.

What conclusions are we to draw from this analysis? Firstly it may be over-optimistic to conclude that people with epilepsy are good to excellent workers (Zielinski, 1984). Secondly, as McLellan (1986) points out, optimistic findings may only "...provide further evidence that the current thresholds that operate in practice for employing people with epilepsy are still set too high, and that the subgroup of employees who have epilepsy may thus be rather more talented than average" (p8).

Therefore, it cannot accurately be said that there is unequivocal evidence for whether or not work performance is better, the same, or worse. Looking at the literature, it appears that support is given to all three views.

It would seem that the contention that there is no substantial difference, provided the seizures are under control, is the most sensible conclusion that can be drawn from the studies conducted.

"...represented nearly one per cent of all recorded days of absence"(p21). The estimated prevalence of people with epilepsy in the workforce is between 0.4% and 0.2%; therefore the average number of days' absence due to epilepsy per individual in 1969 was between 2 and 4 days. However, to what extent can these figures be relied upon?

In the study by Dasgupta et al (1982), no difference was found between the people with epilepsy and the people without epilepsy in respect of sickness absence of less than 20 days per year and although differences were noted for absences of more than 20 days it was found that this was unrelated to the epilepsy.

In a survey of 51 patients with epilepsy in Adelaide (Beran & Read, 1980), people with epilepsy viewed themselves as having less absenteeism and being more reliable at work than non-epileptic people. Good absence records are often reported in the literature (Porter 1968; McIntyre 1982). Kettle (1979), in a report for the Association of Disabled Professionals, reviewed 20 research reports on employment problems of people with epilepsy and concluded that people with

epilepsy lost fewer working days due to epilepsy than the average person does because of accident or illness.

In another industrial study, Lione (1961) stated that: "...sickness absenteeism was average or better in 81% of the cases. In 6 of the 11 cases with high sickness absence records, excessive use of alcohol was suspected as being an important factor"(p370). His measure of excessive absenteeism was an absence of more than 15 days total per year or more than four absences per year. He also stated that there was "...no apparent relationship between the occurrence of epileptic seizures and sickness absenteeism"(p370).

In a study by McIntyre (1976) of 29 works doctors who were members of the North West Group of the Society of Occupational Medicine, information was gathered on 147,600 workers. It was concluded that "...in general they [people with epilepsy] are good workers, and once a suitable job has been found for them will give much better service than, say, the heavy smoker who will need time off because of his bronchitis"(p103).

From these studies, it would appear that people with epilepsy at work are unlikely to constitute a sickness absence problem.

5.8 Turnover rate

It is often said that people with disabilities tend to stay in jobs longer than people without disabilities (Kettle 1979). The person with epilepsy is seen as a good worker because "...he wishes to hold his job owing to the difficulty of getting another one"(Porter 1968, p85).

Udel (1960) looked at the length of time someone with epilepsy spends in a job and concluded that "...examination of the average age and average years of service in the company reveals considerable longevity at work, indicating that these epileptics are a stable work force"(p260). Once in employment it would appear that people with epilepsy tend to stay in a job longer than other 'non-disabled employees' (Mittan, 1986). As was suggested by Porter (1968), this may be due to the difficulties of getting another job or the loyalty generated by the commitment of the employer to take them on despite a stigmatising disability.

The general rule of thumb applied by Occupational Health professionals on hazardous occupations is summed up by Cohen (1985): "...the general test should be - are serious hazards likely to be met if there is sudden loss of consciousness?"(p673). He stated that certain occupations were likely to be "...unduly hazardous for the epileptic; these include any associated with fire, water, vats, ladders (for example, painting, window-cleaning), machinery, motor-driving etc."(p673).

This rule may never have been applied consistently. As Jones (1965) points out from a work-place study "...suitable jobs varied according to the processes in a particular works" (p487). There were a large number of restricted jobs due to the hazardous nature of the work, however, "...many jobs entailed duties carried out close to moving machinery; in view of the excellent guarding devices which were applied to these machines and in the light of experience with epileptics at work, the generally accepted advice that epileptics should not be employed near moving machinery was not rigidly followed"(p487).

Lennox & Cobb (1942) also report that the use of safety equipment may, in some cases, mitigate the dangers. "For example, one of our patients works at a height, painting towers. He contends that he is relatively safe in this position because an attack at work leaves him hanging in his safety belts, whereas one in the street might leave him in the path of an automobile"(p574). It should be remembered that the restrictions applied to people with epilepsy are precautionary in nature "...rather than an indication of impairment in the ability to perform work-related functions" (p615-618; Nussbaum & O'Conner, 1977). Therefore, if a job can be made less hazardous by the use of safety equipment or the individual has demonstrated full control over seizures whilst awake then there is no reason why they should not be able to hold down any job. Indeed, the driving regulations reflect this in stipulating that a person with epilepsy can obtain a driving licence if he or she has been free of seizures for two years or had seizures only during sleep for three years.

There are, however, certain classes of vehicles (HGV, PSV) for which a people with epilepsy can never be licensed, even if they have not had seizures since five years of age. This level of

restriction on what are considered to be highly dangerous tasks or activities is carried over into non-legislated restrictions at work. Aston (1964), for instance, states that, even where employees in his survey had been free of seizures for several years and were not treated with anti-convulsants, "...on the basis of their history of epilepsy, [they] still have to be considered as poor safety risks in relation to certain employments, e.g. crane or locomotive driving"(p3).

5.10 Restrictions on equipment use

5.10.1 Visual Display Units

It is perhaps a modern myth that VDUs are a cause of seizures. It has been reported that some people with epilepsy will be steered away from jobs working on VDUs because they have epilepsy, without any reference to medical opinion (Pilling et al., 1989). Photosensitivity within the range of the flicker produced by a VDU, however, is not a general problem for people with epilepsy and is likely to occur in only 1 in 50 cases (McLellan 1986). For people with photosensitive epilepsy, TV is the most likely cause followed by flickering fluorescent tubes, and strobes rather than VDUs. Problems are more likely to be caused by flashing lights being shown on the screen rather than the

working of the VDU. It is estimated that VDUs induce seizures in less than one in 25,000 operators (McLellan, 1986).

5.10.2 Motor vehicles

Epilepsy is a notifiable condition, in other words the licence holder must notify the Driver and Vehicle Licensing Centre if they have epilepsy. The law states that someone who has had a seizure within the last two years will not be allowed to hold a vehicle licence; if however, they have only had seizures during their sleep for the past three years then they may hold a licence. Both rules are dependent upon the GP certifying that the person is not a risk to the public or themselves (Espir & Godwin-Austen, 1985). The withdrawal of a driving licence is one of the main areas of discontent for people with epilepsy. The restrictions apply to any type of seizure regardless of whether the individual gets a warning of the approaching seizure. According to the DVLC, a single epileptic seizure constitutes epilepsy. A person will be debarred from holding a commercial licence (HGV, PSV or taxi driver's licence) if they have had a seizure since the age of five years. These regulations apply to HGV (exceeding 7.5 metric tonnes laden weight) and PSV (nine or more seats for hire or reward) and the taxi driver's licence.

For someone holding a vocational licence, a single seizure will result in its immediate and permanent withdrawal.

The arbitrary two year rule may seem a reasonable compromise but many people with epilepsy see this as unreasonable and see it as forcing them to be dishonest. The arbitrary nature of the rule is highlighted by the fact that it does not apply everywhere. In some states in America, a period of six months free of seizures is sufficient to make one eligible for a driving licence (Fraser et al, 1983). Many people with epilepsy feel passionately about this issue because the loss of a driving licence will often affect a person's ability to get a job and affect their social status (Fraser, 1981). Despite the apparent clarity of the law, there is still some doubt about the application of the rules. In one survey of 125 British neurologists, Hopkins & Harvey (1983) found poor comprehension of the driving regulations and "...when it came to 'grey areas' confusion ruled"(p15, Harvey & Hopkins, 1983). The medical profession sometimes finds itself in a dilemma over advice to people with epilepsy on this issue since, following a first seizure, it is not possible to say if subsequent seizures will occur and yet a single seizure is sufficient to have the

driving licence removed. Also, some people who (in the strict medical sense) would be considered to have active epilepsy may be perfectly capable of driving safely (Whitty 1968) for example someone who has seizures only upon waking or who gets a reliable and lengthy warning of a seizure.

Added to this there is some evidence to suggest that the risk of someone having a serious accident while driving is very small (Kirboe, 1971). Kirboe assessed the risk of a serious accident to be one hundredth of the risk of a seizure occurring if someone drives for two hours per day. However, Taylor (1983) found that epilepsy or a suspected attack was the most common cause of collapse at the wheel causing an accident. (38% involved a witnessed generalised seizure; 23% were 'blackouts' of which probably half were due to epilepsy.) "It is very worrying that of those collapsing due to a witnessed generalised seizure, 70% had not declared their epilepsy and 12% were experiencing a first attack"(Craig & Oxley, 1988. p591).

It is due to the belief that epilepsy equates with an increased likelihood of accidents that employers often justify discriminating against people with epilepsy (Quadfasel & Guhleman, 1952; Lindsay, 1982). Once in work, an accident or fear of an accident may result in the individual being dismissed (Moollabhai vs GEC Telecommunications Ltd). There can be no doubt that "...akinetik attack(s) in which the patient may fall straight backwards or alternatively straight on their face have an increased incidence of personal injury" (p4, McLellan, 1986).

The consequences of a seizure at work may be very serious; however, discrimination applies even in situations where an accident would have little or no effect. Furthermore, discrimination does not take into consideration the effectiveness of anti-convulsant drugs and the actual frequency of seizures at work. Benson (1989) finds that "...employers' attitudes and employment practices discriminate against hiring persons with epilepsy despite the demonstrated effectiveness of anticonvulsant drugs and despite findings that persons with epilepsy are safe workers"(p1).

The fear that seizures will lead to accidents is widespread, so what evidence can be found in the literature?

Only a few studies have been conducted which have looked at the experience of people with epilepsy in work. These tend to show that people with epilepsy do not have any more on-the-job accidents than anyone else (e.g. Lennox & Markham, 1953).

"It seems that an employee with epilepsy is aware that his disability may increase the possibility of accidents and so he is very careful that non-seizure related accidents are kept to a minimum"(p8, Gering 1979-80).

The general finding of many studies is that people with epilepsy are actually safer than the control group. For instance, a much-quoted study in the British Steel Industry by Dasgupta et al. (1982) shows that people with epilepsy have fewer accidents overall (14/45) than people without epilepsy (31/38). (This is a general rate and includes accidents which are not related to epilepsy.) In a study by MacIntyre (1976) of 29 industries in England, accidents related specifically to epilepsy were studied. He found only 18 accidents reported in 10 years out of 177 employees with epilepsy. He concluded that this

low accident rate shows that epilepsy does not play a significant part in causing accidents. A similar finding comes from France, where Industrial accidents for people with epilepsy is given as between 0.075 (Beaussart & Trouilleux, 1974) and 0.087 (Verceletto et al, 1974) as opposed to 0.088 per individual for the whole of France (I.N.S.E.E.).

Other studies are more equivocal. In the United States Udel (1960) reports that the US Dept. of Labor claims 'incidence of work injuries was slightly higher among the epileptics'. Although differences were observed, these were not significant. He concludes that discriminatory practices against people with epilepsy are unwarranted if based on notions of high accident rates. But he points out that there may be two reasons for lower accident rates. Firstly, people with epilepsy are not exposed to the same risk as people without epilepsy because they are not allowed to drive, work at heights or with dangerous machinery, therefore the opportunities for accidents are reduced. Secondly, people with epilepsy who may feel that their jobs are at risk if they appear to be less able than their colleagues (given an atmosphere of discrimination), will conceal the occurrence of an

accident. If either or both of these conditions are correct the level of accidents is likely to be, or appear to be, reduced.

A case which is not subject to these biasing factors is found (reported by Burden, 1974) in Epi-Hab, an industrial workshop in Los Angeles which employs only ex-army veterans with epilepsy. The workshop assembles light industrial panels for the aircraft industry. Employees are most unlikely to lose their jobs because of a seizure at work as this is probably part of a routine day.

Individuals could not be protected from dangerous tasks as there would be no-one else to do them and when this survey was done in 1958 the workshop was likely to have been equipped with what would now be considered unsatisfactory safety equipment and practices. It was found that the accident rate at Epi-Hab "...was substantially less than in a nearby factory employing non-handicapped workers doing much the same sort of work, and that no serious accident over 3 or 4 years was caused by an epileptic seizure at work"(p971, Burden 1974).

Risch (1962) reported that there were 100 industrial accidents recorded at Epi-Hab over a four year period. This impressive safety record has meant that "...Epi-Hab L.A. has received the safety award for 2 consecutive years, and because of its safety record has been given insurance premium reductions approximating 20 percent."

(p68, Risch 1962)

Examples of decreased risk can also be found. In an industrial study conducted by Lione (1961), 58 people with epilepsy at two oil refineries in USA were surveyed. All subjects had a definite diagnosis of epilepsy, with full clinical evaluation data made available (including physical and neurological examination). Lione reports that "...there were 49 employees with no disabling injuries, while 8 suffered one or more off-the-job disabling accidents and 1 had an industrial 'losing-time' accident"(p370). Nearly half of the off-the-job accidents related to seizures, the excessive use of alcohol being identified as an important factor. Lione (1961) states that "...less than seven per cent of the industrial injuries of epileptics are due to seizures"(p372). Lione concluded that "The fear of an increased accident rate among epileptic employees does not appear justified"(p372).

There is, therefore, no evidence that people with epilepsy are more likely to have accidents than anyone else. Discrimination on the basis of accidents derives from the exceptional cases being transformed into generalities (Beaussart-Defaye, 1984). However, if seizures are perceived to lead to accidents at work, Vroom (1964) argues that this will result in general dissatisfaction of all workers because colleagues start to see the job or work-place as unsafe. It is therefore in the interests of the employers to inform the work-force of the real chances of a seizure occurring and the real consequences if one does occur.

This chapter has looked at the literature concerning epilepsy and employment from the occupational perspective and has divided this into two distinct and important areas for the analysis of any organisation. These have been the occupational issues and the human factors aspects of the work.

This chapter has identified that the culture of the organisation may be a significant factor in the person with epilepsy being accepted by work colleagues. Culture is derived from the general view of epilepsy and from the advice available to it. We have also seen that advice may not always reflect the individual nature of the problems encountered in the work place.

The main points encountered in this chapter are:

- 1) For the person with controlled seizures, there may be unnecessary restrictions which hold them back in their careers.
- 2) The type of work that can be undertaken by someone with epilepsy is restricted; this is especially true if the seizures are active.
- 3) Epilepsy can be viewed as a human resource issue where management is not in possession of all the information it needs to control the situation.

- 4) Studies indicate that a large number of people with epilepsy have seizures at work. However, it is speculated that the seizures may have little effect because they result in only short breaks in production.
- 5) Shift work may affect the seizure pattern of some people and is advised against by some physicians. The susceptibility to problems caused by shift work is likely to vary between individuals.
- 6) The level of disruption caused by a seizure at work will depend on the suddenness of the seizure, the type of seizure and the duration of the post-ictal recovery period.
- 7) The work performance of people with epilepsy has been questioned by some researchers and employers but overall there is no evidence that epilepsy affects production rates.
- 8) Sickness absence can be high for some people with epilepsy but there is no indication that the average person with epilepsy will take more sickness absence than other workers.
- 9) The turnover rate for people with epilepsy is low.
- 10) Employers' judgement of risk is based on general opinions and does not consider individual circumstances.

11) Employment restrictions are sometimes applied without reference to medical opinion. This appears to apply to restrictions on VDUs.

12) Accidents are shown to be a fairly rare occurrence and should not be seen as a significant factor in the employment of someone with epilepsy.

CHAPTER SIX
LEGAL AND STATUTORY ISSUES

Contents

6.0	Overview
6.1	Health and safety legislation
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6.5	Employment quota
6.6	Insurance
6.7	Pension schemes
6.8	Summary and main points

6.0 Overview

This chapter will describe employment and statutory regulations related to epilepsy. This includes both general obligations that the employer has towards people with disabilities and the restrictions against employing people with epilepsy in jobs identified as high risk. The main point of this chapter is to demonstrate that the legislation is complex and often ambiguous.

The legislation of most importance to people with epilepsy at work is that relating to health and safety as encoded within the Health and Safety at Work Act 1974 and in common law. In addition to this, there are also acts relating to employment

protection and the employment quota. Insurance and pension scheme liabilities will also be considered in this chapter.

6.1 Health and Safety Legislation

Obligations under the health and safety laws may act as a disincentive to employers to recruit someone with epilepsy. By taking on someone with epilepsy, the employer has the same responsibility as to other workers to provide satisfactory arrangements to avoid health risk or injury. The legislation is intended to increase safety for everyone by promoting health standards and safer working practices. However, these requirements could be interpreted as being restrictive to employment. It is worth describing here how this might come about. There are two areas from which legal duties are derived: common law and legislation.

Common law is created mainly by decisions made by the courts. These decisions then form precedents for legal actions taken in the future. A duty of care arises for the employer under the general law of civil wrongs and torts when the actions of the employer result in a risk of injury to the employee. There is not an absolute duty to ensure

safety at all times; however, the employer is expected to obey statutory duties and to take reasonable action to provide a safe working environment and working practices. A legal action taken against an employer would have to prove that the employer was negligent in these duties. For instance, negligence could be proven if the employer did not provide adequate protective equipment, or has employed people who are not competent. It is here that the problems for people with epilepsy arise. So little is known or so little information is made available about the competency of people with epilepsy at work that an employer may justifiably feel unqualified to make a judgement on the employability of a person with epilepsy.

The main piece of legislation relating to health and safety at work is the 1974 Health and Safety at Work Act, which has the objective of maintaining or improving health, safety and welfare at work. This is achieved by obligations placed on the employer towards employees and others, and obligations placed on the employee to take reasonable care of themselves and others. The Act does not specifically refer to people with disabilities or to epilepsy but applies to people in general. However, epilepsy would be seen as a

special condition of the employee and as such would need to be taken into consideration by the employer when allocating work duties and assessing the risks.

Under the Act, the employee has a duty to declare the condition to the employer so that reasonable care can be taken. Declaration of a disability is not a legal requirement of the Act and, except in certain professions where separate statutes arise, would not be a prosecutable offence. Where there has been failure to disclose a disability, dismissal is not automatic and will depend on the circumstances of the case. Such factors as insurance (*Jary v Sandoz Products*) and safety (*Mitchell v Dust Control*; *Harper v NCB*) would need to be compromised for dismissal to be considered 'fair'. The Employment Medical Advisory service (EMAS) recommends that "...an employee, or a prospective employee should disclose his medical condition to an employer if there might be health and safety implications in the particular job concerned" (Carter, 1986). Whether the epilepsy is declared or not, the employee also has the responsibility not to place themselves or others at risk where they know an accident might occur due to seizures.

Her Majesty's Factory Inspectorate stated in 1986 that there had not been a single prosecution of an employer or employee related to epilepsy in the previous ten years (Carter, 1986).

6.1.1 The Employment Medical Advisory Service

The Employers Medical Advisory Service (EMAS) is a part of the Health and Safety Executive which offers free advice to employers on health and safety matters. An employer would be considered to have taken reasonable action if they had consulted the EMAS on the employment of a person with epilepsy and taken that advice into consideration when allocating work.

6.2 Employment Protection Provision

The Employment Protection (Consolidation) Act (1978) provides the conditions under which dismissal on medical grounds is considered fair. There are five basic reasons for fair dismissal, two of which are particularly important to someone with epilepsy: capability to do the job and illegality.

6.2.1 Capability to do the job.

Dismissal is considered fair where the employer is able to show that the employee is not capable of performing the work satisfactorily due to ill health, or where the individual constitutes a danger to others. These situations may arise where the employee's capability has deteriorated since starting work, or from the work changing and becoming more complex, faster or strenuous. The decision to dismiss is considered on the basis of whether it is reasonable in the circumstances to go on employing this person. At a tribunal, if there is satisfactory evidence to show that the person cannot continue their job satisfactorily, the employer must also be seen to be using a fair procedure for the dismissal. This would include:

- i) discussing with the employee the problem, taking into account the disability;
- ii) looking for a suitable alternative job in the company;
- iii) considering the retention of the employee until work can be found.

Dismissal may be considered fair even if the company is below its quota of disabled employees (Seymore v British Airways Board).

6.2.2 Illegality.

Another reason for 'fair' dismissal under the Act is 'Illegality' e.g. if someone with a driving job becomes ineligible for a driving licence due to epilepsy then this would be fair grounds for dismissal.

6.3 Poor attendance.

Under common law the employer may find it difficult to dismiss someone on the grounds of poor attendance. Employers taking on someone with a disability will be expected to tolerate a higher level of poor attendance than from a non-disabled person (Kerr v Atkinson Vehicles).

6.4 Employment Discrimination

The refusal to employ someone because of their disability is not covered by the present discrimination laws. It is, however, quite legal for an employer to introduce some health questions into their recruitment process with or without any medical input into the design of the questions or their interpretation. This situation is unlikely to change as there is a move away from statutory obligations on employers in this area towards the promotion of voluntary equal opportunities policies (Department of Employment, 1990).

The 1944 Disabled Persons (Employment) Act established a 3% employment quota for industries employing more than 20 employees. A person with epilepsy who is registered disabled, due to severe employment handicap, would be considered as contributing to the 3% quota employers are obliged to recruit. However, the quota scheme has been recognised as unworkable and its benefit to people with disabilities is considered minimal (Dept. of Employment, 1990).

The Employer's Liability (Compulsory Insurance) Act of 1969 obliges employers to take out insurance to cover injury and disease that might arise from their work. The Act covers all employees, including people with epilepsy. Some insurance policies may not cover people with disabilities but most policies will treat anyone with a disability on the same terms as the able-bodied employee providing that the duties allocated to the person with a disability take the disability into consideration.

This is one of the major considerations mentioned in discussions about the employability of people with epilepsy. The alleged threat of an increase in accident insurance rates is the most frequent reason given by employers for not taking on someone with epilepsy (Goodglass et al, 1963). On the face of it, it seems that concern over employment insurance is unfounded. In 1958 Cohen stated that "...employers may fear that epileptic employees expose them to special legal liability in the case of accidents at work, but provided the employer takes reasonable precautions there is no specific liability and the National Insurance (Industrial Injuries) Act 1946 covers epileptics in the same way as other workers"(p673).

However, this statement hangs on what is meant by 'reasonable precautions'. Insurance companies are unlikely to enter into a dialogue on what are 'reasonable precautions' in specific cases until after an accident has occurred. Employers may therefore feel that they are unprepared to take the risk and save themselves trouble in the future by not employing someone with epilepsy. This may be especially true in a small organisation where the tasks of a job are not fixed and an employee may be expected to undertake different jobs at different times, making it difficult for the

employer to keep track of reasonable precautions. Such problems are less likely to occur in larger organisations where job boundaries are more fixed.

There appear to be no data on the problems employers have had in obtaining insurance but there is some evidence of problems for the individual in getting adequate insurance at a rate they can afford. Dell (1986) reports that the Commission for the Control of Epilepsy (1978) noted that "...52% of the respondents to a survey experienced problems obtaining life insurance, 40% had problems obtaining medical insurance, 37% accident insurance and 32% auto insurance"(p201). At first this may seem to be another case of prejudice but, in defence of the insurance companies, Peper (1987) points out that insurance rates are based on tables of mortality rates. These have to be compared to the prevalence rate in order to be useful, but, as we have seen in Chapter 2, it is very difficult to get accurate information on prevalence. The figures used by the insurance companies may therefore be under-estimating the size of the epileptic population and thus over-estimating the dangers of epilepsy.

It was pointed out at the 1990 Epilepsy and Society conference (in Dublin) that although some companies did not insure people with epilepsy at the same rates as others, this could be changed if the medical profession were able to give the insurance profession more details of accident and death rates.

6.7 Pension Schemes

Many employers and occupational physicians believe that high standards of health are required for new recruits to their pension schemes. However, the Occupational Pension Board (1977) states that if a person is fit for employment then they are fit for a pension scheme. Employers should only be concerned with the placement of the individual in respect of their ability to perform the job safely.

There are several pieces of legislation which concern the person with epilepsy at work. The most important relates to health and safety. Health and safety legislation may deter employers by placing ambiguous duties of care on them. Employers are expected to determine what are reasonable precautions but this may be felt to be beyond their expertise; the easiest solution then is not to employ the person with epilepsy.

Under this legislation the person with epilepsy has a duty to declare epilepsy to an employer. Employment protection is limited where the employer can show that the employee did not declare the epilepsy or where the employee is no longer capable of the work. It is not illegal for an employer to discriminate against someone on the basis of their epilepsy. A major excuse for not employing someone with epilepsy is the infringement of insurance policies and pension rules. However, most employer insurance policies and all pension policies will cover people with epilepsy provided that duties allocated are done so in relation to the disability of the individual. Again, employers may not feel

confident to make these judgements. They may thus be encouraged to take the safest option which is not to employ the person with epilepsy.

The legal and regulatory disincentives to the employment of people with epilepsy are:

- 1) under the health and safety laws employers are obliged to have a safe working environment; where it is unclear what risks the person with epilepsy brings to the work place, this rule may act as a disincentive;
- 2) under the Employment Protection Act the employer is expected to make a judgement on what is reasonable in terms of employment for a person with epilepsy; although dismissal on the grounds of epilepsy is legal, the employer will be expected to assess the viability of other jobs in the company and consider retention until other work can be found;
- 3) there is no recourse under law for discrimination on the basis of disability. If someone is rejected from a job solely on the basis of having epilepsy there is no come-back in law.

The legal and regulatory structure also contains incentives to employ people with epilepsy:

1) the most positive piece of legislation is the quota scheme in which employers are obliged to recruit 3 per cent of their workforce from people with disabilities. However, this is not enforced and obtaining a waiver from the Department of Employment is made very easy. As a consequence, very few companies employ 3 per cent people with disabilities;

2) Insurance liability and pension schemes are designed for the whole work force and if the workforce includes people with epilepsy then they are also covered. Although this ought to act as an incentive, the nature of the insurance schemes is poorly understood by employers, who may view insurance liability as a disincentive.

The main points of this chapter are:

1. Health and Safety law may act as a disincentive to the employment of a person with epilepsy.
2. Employer's fear exposure to legal liability in the case of accidents at work.
3. It is difficult to get firm judgements on liability from insurance companies.
4. People with epilepsy have difficulty in obtaining insurance.

5. Pension schemes are inclusive of all employees but this is often not appreciated by employers.

6. In order to employ a person with epilepsy the employer needs to know that they are not infringing health and safety law, insurance and pension rules.

7. The laws and rules applying to people with epilepsy are often ambiguous enough to warrant a manager being uncertain about an employment decision.

CHAPTER SEVEN

ISSUES FOR EMPIRICAL INVESTIGATION

Contents

7.0	Overview
7.1	Medical issues
7.2	Psychosocial issues
7.3	Management issues
7.4	Legal issues
7.5	A framework for empirical analysis

7.0 Overview

From the foregoing analysis of the literature, a number of variables have been suggested which may affect the employment of the person with epilepsy. We have also seen that there are a number of issues which are unresolved, in need of replication or require further investigation. In this chapter I shall develop a list of questions which require empirical investigation. This will form the framework for analysis of the experiences of people with epilepsy at work, which will be undertaken in Part Three.

Most of the evidence for the effects of the medical aspects of epilepsy on employment have come from patient series drawn from clinic or hospital populations. Studies have generally been carried out in non-working environments and because of this, very little is known about epilepsy at work and whether it is possible to predict good or bad work performance or high unemployment on the basis of medical factors.

Seizures are often presented as the main problem for employment. However, it is unclear from the literature what the actual relationship is between seizures and work. On the one hand, there is evidence that people with quite high seizure frequency can and do maintain a job without loss of work performance or increased sickness absence. On the other hand there is some evidence which suggest that seizures can constitute a problem and are likely to lead to unemployment and reduced career opportunities; indeed common sense would support this. We have considered that the lack of consistent findings may be because the type of seizure has not been considered, and because of variations in the statistical procedures adopted.

On the basis of the literature there are several questions in need of further research and conclusions in need of clarification. Those I have identified from this review are:

- 1) There is a suggestion that seizure type or a mixture of different types, which includes generalised seizures, may be detrimental to employment. Can a mixed seizure pattern be demonstrated to be occurring in a working population?
- 2) There is inconclusive evidence on the effects of seizure incidence on employment. Clearly there are people with active epilepsy found in the work-place but we don't know if they have particular problems which make employment difficult. Therefore we can ask: does having active epilepsy make a difference to successful employment?
- 3) More convincing evidence is available to suggest that it is the increase in seizures which is likely to have the most negative effect on employment, but this evidence comes from a single study. Can this be replicated in a British working population?

- 4) It is suggested that the warnings (auras) which some people get prior to a seizure can help to increase the chances of someone retaining employment. Can evidence be found to support this claim?
- 5) The length of time taken to recover from the seizure is suggested to affect employability. Can supporting evidence be found?
- 6) Multiple disabilities are shown to contribute to negative employment effects. People with epilepsy plus another condition or with personality problems are the most likely to have employment difficulties of various types. Can this finding be replicated?
- 7) It has been revealed that some people ascribe precipitating circumstances to their seizures. To what extent is this done in the work-place and what are the stimuli which are thought to bring on a seizure?
- 8) The deleterious effect of an inappropriate medical regimen is well illustrated in the literature. The toxic effects of poorly administered anticonvulsants can result in poor work performance due to drowsiness, blurred vision, lethargy and confusion, among other symptoms. Is there evidence of this occurring in the work force?

9) A major factor implicated in lower employment status is the age of onset of epilepsy. It has been shown that early onset can hinder education by taking the pupil out of school at a critical time and that this may in turn lead to decreased occupational achievement. Can an effect of age of onset be shown in a working population?

10) The literature indicates that the onset of epilepsy can occur at any age and therefore it must occur in the work-place. However, this is a factor which has not been covered adequately by the literature. What are the consequences of the onset of epilepsy occurring whilst in employment?

7.2 Psychosocial issues

Personality differences have been associated with people with epilepsy but there is no evidence to show that this is a consistent finding unbiased by other variables. Despite this, there is a persistent belief that differences do occur.

One reason suggested for personality differences is the idea that the experience of having epilepsy and coping with the influence that it has on one's life will affect personality development. It has also been argued that random and unpredictable seizures could lead to feelings of helplessness in

people with epilepsy. This helplessness is learned in the sense that people with epilepsy discover that they are unable to effect a positive change over stressful events (seizures) in their lives.

It has also been said that stigma may be one of the biggest barriers that people with epilepsy have to face, marking the divide between acceptance and non-acceptance. For stigma to exist, it must be the opinion of the society (a collective image) that there are differences between the people with epilepsy and people without epilepsy. Not only must differences be perceived to exist but they must be considered to be important. It is clear that the collective image of epilepsy is felt by society generally to make very distinct the difference between people with and without epilepsy. This image is based upon a stereotype possibly derived from myths about epilepsy and the connection between epilepsy and mental illness erroneously made in the past. These beliefs are widely held and therefore must be held by employers and employees alike. As such they can affect the employment prospects of someone with epilepsy.

The following questions related to the problems at work can therefore be identified:

- 1) If epilepsy affects personality development, can evidence be found that people with epilepsy have more behavioural problems at work?
- 2) How does the stigma that is attached to the condition of epilepsy manifest itself at work? What are the attitudes of co-workers and managers?
- 3) If social support can be shown to alleviate the feelings of stigma, can it be demonstrated that people with problems at work also have social support difficulties?

7.3 Occupational issues

I have identified that a major problem area for employment is the level and accuracy of advice that is available to the manager and employees.

One example of this is the advice offered on the type of work that is suitable for people with epilepsy. From the literature it is possible to identify two approaches to identifying appropriate work. The more positive approach is to look at the abilities of the individual first, whereas the negative approach is to start by classifying jobs which cannot be done (based on generalisations about epilepsy). When applying the positive approach, people with epilepsy can be seen to be able to employ the skills necessary for many

different types of occupation. It has been shown that there are many jobs open to the person with epilepsy if the risks are considered in relation to the individual manifestation of the epilepsy. What is not clear from the literature is what type of work is actually being offered to people with epilepsy.

Another occupational factor revealed by the literature is the significance of seizures occurring at work. Disruption resulting from seizures is dependent upon several factors which have not been studied consistently in the work-place. A major seizure occurring without warning will be disruptive and could result in loss of work time, not only for the individual having the seizure, but also for work colleagues who have to take care of the individual both during the seizure and in the post-ictal stage if there is confusion.

It has been suggested that certain employment-related factors may be implicated in the precipitation of seizures. For instance, people may cite stress as a precipitating factor likely to occur at work. Because there is this possible relationship between events at work and

the generation of seizures, employers may feel justified in not employing people with epilepsy. This relationship therefore requires examination.

The research on work performance is contradictory and one of the reasons for this can be identified as the lack of a consistent definition for work performance used across the studies. The research reported thus far cannot be judged as giving unequivocal evidence one way or the other but, according to people with epilepsy, their work performance is no different to anyone else's. Equally, it has been proven that people with epilepsy take no more time off due to sickness than other workers. These findings may be non-intuitive to employers, given the present organisational culture, and therefore more evidence is needed to refute the belief that people with epilepsy have high levels of sickness absence.

The literature indicates that there is no evidence that people with epilepsy have more accidents than anyone else. This again is a finding which is counter-intuitive to the organisational culture in which most people with epilepsy will find themselves. We therefore need to gain more evidence on this issue.

From the foregoing, it is identified that the following occupational issues require further investigation:

- 1) The literature suggests that seizures are likely to be occurring at work. Can this be confirmed and, if so, what effect does this have on sickness absence and work performance?
- 2) When seizures occur at work, the literature implies that the work-place could be greatly disrupted. However, there is no empirical evidence to suggest what disruption is caused by seizures at work. Can disruption be identified?

In addition to these questions, there are also six questions which indicate that a problem is occurring. These may be viewed as the dependent variables in the analysis.

- 1) There is the suggestion in the literature that people with epilepsy, where the seizures are controlled, can be employed in virtually any job. Can it be identified that people with epilepsy are employed in a wide range of occupations?
- 2) There is no indication of lower work performance by people with epilepsy. Can this be confirmed?

- 3) There is no indication of high sickness absence for people with epilepsy. Can this be confirmed?
- 4) Shift work is advised against by medical opinion. Is there evidence that people with epilepsy are doing shift work?
- 5) Restrictions may be based on generalisations about epilepsy. How are restrictions at work applied?
- 6) The literature suggests that accidents are a major worry for employers. Can evidence of accidents at work be found in a working population of people with epilepsy?

7.4 Legal issues

The current legal structure in the U.K. relating to people with epilepsy is two-fold. On the one hand there are obligations placed on employers to employ people with disabilities and assistance is given by the government to encourage employers to take on people with disabilities. On the other hand there are restrictions, in specific employment areas, on the employment of people liable to have seizures. These professions tend to be mostly concerned with transport, where risks are considered to be unacceptable.

In order to encourage a safe working environment, the employee with epilepsy is obliged by law to declare that they have epilepsy so that reasonable care may be taken by the employer in the allocation of duties. As long as care is taken, there should be no restrictions on the employment of someone with epilepsy in terms of the insurance liability or the pension rights of the individual.

From this analysis the following questions are suggested:

- 1) The legal picture encapsulates the socially generated circumstances that state that the person with epilepsy is both normal and yet different. General advice is likely to be cautious if there is any doubt at all about someone having a seizure at work. What advice can be found being offered to the employee?
- 2) Occupational Health advice may be based on generalisations. What evidence is there that occupational health advice is being offered on the basis of the individual circumstances?

7.5 A framework for empirical analysis

In Part One of this thesis we discovered that epilepsy is more than one thing; in fact it should perhaps be seen as a category of conditions called 'the epilepsies'. The clinical manifestations of epilepsy will be different for each person and the experience at work may also be different for each individual. We also found in Part One that there are many potential employment problems for people with epilepsy. The most serious problem for someone with epilepsy is that they are unable to get a job, and it can be seen that people with epilepsy are overly represented in terms of unemployment. However, there are other problems facing the person with epilepsy once they have gained a job. Firstly, the type of job obtained may be below their capabilities; secondly, they may be restricted in their careers and have to change jobs more frequently, with the consequent risk of unemployment.

From Part Two we have found that despite a large literature on the issue of epilepsy and employment, there is no consistent evidence for a significant effect of the different variables examined and no theoretical analysis available to

explain the problems. The literature review has produced a number of questions which need to be answered and a number of ambiguous findings which need to be explored in more depth. The medical, psychological and some occupational variables I have identified constitute a systemic framework for the formulation of a biopsychosocial model (Engel, 1977, 1982) which could be used to develop an explanation of the complexity of the employment problems of people with epilepsy. However, the relationship between these variables and the work situation (dependent variables) needs to be clarified before a theoretical model can begin to emerge. In order to test this framework we need to take our investigation into an open working-environment. In Part Three we shall survey working populations of people with epilepsy to determine the importance of the different elements of the biopsychosocial framework and determine whether evidence to support the framework can be identified. Table 7.1 sets out the framework which will allow us to examine empirically the problems of epilepsy in greater detail.

<u>Table 7.1</u>	<u>A biopsychosocial framework</u>
	(Dependent variables)
	1. Job type
	2. Work performance
	3. Sickness absence
	4. Shift work
	5. Restriction to employment
	6. Accidents at work
	(Independent variables)
Medical issues	7. Seizure type
	8. Incidence of seizures
	9. Increasing frequency
	10. Warnings / aura
	11. Recovery time
	12. Co-incidental disorders
	13. Factors causing seizures
	14. Drug side effects
	15. Age of onset
	16. Onset after employment
Psychosocial issues	17. Behaviour at work
	18. Attitudes of manager and co-worker
	19. Disrupted education
	20. Social problems
Occupational issues	21. Seizures at work
	22. Disruption due to seizure

The goal of the empirical studies as a whole will be to draw conclusions on each of the elements. It will, however, not be possible to test all the above elements in each of the studies. A discussion of the framework in the light of the empirical evidence will be found in Chapter Eleven.

PART 3

WORK PLACE SURVEYS

Chapter 8	The pilot study at BP
Chapter 9	The Civil Service Study
Chapter 10	The National Health Service Study

CHAPTER EIGHT

THE PILOT STUDY AT BP

Contents

8.1	Introduction
8.2	Method
8.3	Demographic characteristics
8.4	Employment problems
8.5	Testing the biopsychosocial framework
8.6	Summary
8.7	Evaluation of the study

8.1 Introduction

British Petroleum (BP) Occupational Health Department requested research into the question of epilepsy at work within their offices in London. An Occupational Physician from British Petroleum, who had been instrumental in setting up a computerised occupational health data base, assisted with the identification of potential respondents and advice on BP procedures.

The aims of this pilot study were to conduct a preliminary investigation of issues related to epilepsy and employment, to assess the value of a questionnaire approach and to assess if employees with epilepsy would be prepared to talk about their experiences. Attention was also paid to any new issues which had not been considered by the literature.

8.2.1 Identification of respondents

The sample population was identified through the BP Occupational Health Department computerised health records system. A total of 24 employees with epilepsy were identified in a population of 7000. This is an prevalence of 3.4 per 1000 employees. The definition of epilepsy used by the BP Occupational Health Service is very broad and includes anyone who has had a history of epilepsy. If a more narrow definition of epilepsy is used (see section 2.6), including only people who have had a seizure within the last two years or who are currently taking anti-convulsant medication, the prevalence of this group in the BP population is 9 respondents, a prevalence rate of 1.3 per 1000.

8.2.2 Procedure

Data for the study were collected in two formats: from a detailed self-completion questionnaire and from a semi-structured interview. The questionnaire was composed of questions related to health, psychosocial factors and employment. The questionnaire used was a pilot version of that being written for the Civil Service study and is further described in the next chapter. The final version of the questionnaire as used in the Civil Service study can be found in Appendix 1.

Questionnaires were sent from the BP Occupational Health Department with instructions that they should be returned through the internal mail system, addressed to the City University, care of the Occupational Health Department. Addressing the questionnaire to the City University was intended to increase the response rate by increasing the level of respondents' confidence in the anonymity of the survey. The questionnaire was comprised of multiple choice questions.

Interviews were of one hour in length and held at the BP Occupational Health Department. Interviews were conducted with seven respondents. The data

collected from these interviews were used to clarify medical and occupational information given on the questionnaire. Interviewees were given the opportunity to talk openly about issues that they thought were important. Fourteen people completed the questionnaire, a response rate of 58% and seven respondents attended for interview.

8.3 Demographic characteristics

The majority of respondents were male (11 respondents) and married (11 respondents), the ages ranged from 23 to 52, with a mean age of 37. None of these respondents was registered as disabled.

Table 8.1 Age range of sample

Age	Male	Female
23 - 25	1	1
26 - 30	1	-
31 - 35	1	1
36 - 40	5	-
41 - 45	-	1
46 - 50	1	-
51 - 52	2	-

The educational background of the respondents was good, five having studied at University level. Professional qualifications were also obtained by two of the respondents.

8.4 Employment problems

During the interviews, a number of respondents referred to problems they had in terms of understanding the restrictions that had been placed on their careers and a wish to know more about the criteria that would be used to make judgements on their future employment with BP.

Overall the group was judged by the BP Occupational Health Department to be free from employment or health problems.

Interviewees were asked if there was any information they wished they had been given when they first started work. Many of the interviewees said that they had received no information. They felt that the most important thing was to be told that epilepsy was not as serious a handicap to work as it was often thought to be. One interviewee felt that he had derived benefit from having epilepsy because it had presented him with a challenge to prove that he was not disabled and this, he felt, had given him extra motivation to try that bit harder.

8.5 Testing the biopsychosocial framework

In this section I shall examine the elements of the biopsychosocial framework described in chapter seven (see table 7.1).

Dependent variables

8.5.1 Type of job

The respondents had been employed by BP for an average of nine years, within a range of one to twenty years. The occupations of this group ranged across the spectrum of employment but most of the respondents had attained a senior or managerial position. The list of occupations given below is divided into three areas, corresponding to the job descriptions of the respondents: Managerial, Technical and Clerical.

Table 8.2 Occupations within the sample

	Age	Sex	Job title
Managerial/ Technical	40	m	Manager, Services
	48	m	Project manager
	52	m	Head of department
	52	m	Tax manager
	30	m	Market manager
	34	m	Analyst
	36	m	Fire Engineer
	37	m	Mechanical Engineer
	38	m	Planner
Clerical/ Manual	22	f	Records Assistant
	23	m	Senior Records clerk
	33	f	Senior Secretary
	37	m	Messenger
	41	f	Secretary/Administrator

A division of this variable based on a distinction between management/technical and clerical/manual lent itself to use as the dependent variables in the statistical analyses.

8.5.2 Work performance

An objective measure of this variable was not available in this study.

8.5.3 Sickness absence

Only one respondent in the sample had taken more than a few days sickness absence in the last 24 months. This respondent took two weeks absence related to epilepsy. She was having frequent tonic-clonic seizures during this period.

8.5.4 Shift work

None of the respondents were doing shift work as a standard part of their job. However, many of the respondents in the senior posts were expected to do overtime. This was not viewed as a problem by the Occupational Health Department.

8.5.5 Restrictions to employment

No specific restrictions in terms of tasks in their current jobs were being applied. However, all interviewees, especially those with non-active seizures, expressed a need for a clearer set of guidelines on how their condition was viewed by the company. For instance, two interviewees had been told that epilepsy could prevent an employee from being posted abroad, often a requirement for career progression in BP, however, they were uncertain of what definition of epilepsy was being used and uncertain whether this ruling applied to them. In both cases the interviewees had not had a seizure for some

years. Neither was it made clear to them under what criteria could they expect restrictions to be lifted.

8.5.6 Accidents at work

Only one seizure had caused injury in the last twenty-four months. According to the respondent's report, a tonic-clonic seizure had caused slight injuries to herself but no one else was injured. This respondent was having frequent tonic-clonic seizures and had the highest seizure frequency in the group.

Independent variables

8.5.7 Seizure type

Eight respondents (57%) said that they had tonic-clonic seizures in the past. Four said they had tonic-clonic seizures as their only seizure type. One respondent in the 'active seizure' group (N=8) was having tonic-clonic seizures as her main seizure type and one other respondent was having a mixed generalised and partial seizure pattern. All other members of the 'active seizure' group were having partial seizures. The most frequent seizure type was partial seizures. For statistical purposes a division is made into two groups: a seizure pattern including

generalised seizures and other patterns (not including generalised seizures). There is no difference between seizure type and job type (Fisher exact $p>0.21$).

Table 8.3 Type of seizure compared to job type

	Inc. generalised	Other
Management/technical	4	5
Clerical/manual	4	1
	NS	

8.5.8 Incidence of seizures

Eight respondents considered themselves to be free of seizures. However, of these, one respondent had had a seizure in the previous twelve months, and another said that, although he couldn't remember the last time he had had a seizure, he still has "what the doctor refers to as myoclonic spasms". If these two respondents are removed from the 'seizure free' group (N=6 43%), the average length of time since seizures occurred was twelve years. For those respondents in the 'active seizure' group (N=8 57%) the average time since their last seizure was ten months ranging from five to seventeen months. The

respondent with the highest seizure frequency had a seizure on average once or twice every six months.

The following table relates the type of job (managerial/technical, clerical/manual) to the occurrence of a seizure in the last 24 months.

Table 8.4 Seizures within last 24 months

Job type	Seizures within last 24 months	
	Yes	No
Management/Technical	3	6
Clerical/Manual	5	0

p=0.028

It can be seen from this table that a possible trend emerges: employees with active epilepsy tend to be concentrated in the clerical/manual jobs. A Fisher exact test reveals that the possibility of observing this distribution or one more extreme is $p=0.028$. We are therefore able to reject the null hypothesis (at $\alpha=0.05$) of no difference between these groups. However, the sample size is small and therefore caution must be used in the generalisation of this result to other populations.

8.5.9 Increasing seizures

None of the respondents reported a recent increase in seizure frequency.

8.5.10 Warnings / aura

Most of the respondents (eight) had received warnings (aura) prior to the occurrence of seizures. In five cases, respondents had received warnings prior to every seizure and in all these cases the warning had given enough time for the respondent to seek safety.

Table 8.5a Frequency of warning (aura)

Warnings	Frequency
Always aura	5
Enough time to seek safety	5
Usually aura	2
Enough time to seek safety	1
Sometimes aura	2
Enough time to seek safety	1
Never aura	5

If the two extremes of the range ('always has aura' and 'never had aura') are compared to the dependent variable of job type, no significant difference is shown between always having an aura and never having an aura (Fisher exact $p=0.083$).

Table 8.5b Aura compared to job type

	Always aura	Never aura
Management/technical	5	2
Clerical/manual	0	3
NS		

8.5.11 Period of confusion following a seizure

The period of confusion or lack of awareness associated with a seizure was estimated by the respondents to last anywhere from a few seconds to three hours. The median period was ten to fifteen minutes but the most frequent response was 'a few minutes'. There was no relationship between this variable and type of job (Fisher exact $p>0.17$).

Table 8.6 Period of confusion compared to job type

	Less than 15 minutes	Greater 15 mins
Management/technical	7	2
Clerical/manual	2	3
NS		

8.5.12 Coincidental disorders

Twelve of the respondents considered that their general health was good or excellent. None of the respondents had any long term illness or disability apart from epilepsy.

8.5.13 Factors precipitating seizures

Only one of the interviewees could identify specific factors which were believed to have precipitated seizures. These factors put the individual under stress, and it was believed that this stress may have caused a seizure. See section 8.5.20 for more details.

8.5.14 Drug-side effects

Nine respondents were taking anti-convulsant medication at the time of the survey, two respondents had never taken anti-convulsant medication. None of the respondents claimed to have experienced any side-effects of medication.

8.5.15 Onset prior to employment

All respondents had onset of epilepsy prior to starting work with BP. The age at diagnosis ranged widely, from six years to thirty-eight years with a median age of fourteen.

8.5.16 Onset after employment

None of the respondents had onset of epilepsy after joining BP.

8.5.17 Behaviour at work

Interviewees reported that having epilepsy sometimes resulted in feelings of stress which could cause irritability and tiredness at work. Six interviewees (86%) said they had had some difficulty in coming to terms with the realities of having epilepsy. These difficulties generated from both the label of epilepsy and from physically having seizures. The difficulties arose in two areas: firstly, the problem of having to tell others that they had epilepsy; secondly, the embarrassment of having a seizure in public. Occupational Health records examined by the BP Occupational Health Physician did not indicate incidence of anti-social behaviour for any of the respondents.

8.5.18 Attitude of managers and co-workers

Interviewees were able to recall adverse reactions to them having epilepsy but these always related to people outside work, either friends or people in the street. Interviewees found that the attitudes of colleagues had been more positive than they had originally anticipated.

Interviewees who had not had seizures at work expected their colleagues' reactions to be one of fear or disgust. Of the reactions encountered, no interviewees were able to give examples of hostile or adverse attitudes. Management reaction to epilepsy differed from one office to another. One interviewee described how she had been made responsible for a disabled person in one office, and then was annoyed to find that when she moved to another office, it was she who was considered to be disabled by her new manager and someone was assigned to be responsible for her. She commented on the different 'unwritten' policies applying in different departments, such that you could not be certain how you would be treated if you changed jobs.

8.5.19 Disrupted education

This variable was not included in this study.

8.5.20 Social support

This variable was not tested in this study.

8.5.21 Seizures at work

Three respondents reported having seizures at work within the past 24 months. In two cases these were tonic-clonic seizures and, in the third, temporal lobe. No relationship was found with job type (Fisher exact $p>0.49$).

Table 8.7 Seizures at work compared to job type

	Seizures at work	No seizures
Management/technical	2	7
Clerical/manual	1	4

NS

8.5.22 Disruption due to seizures

Respondents believed that the disruption due to their seizures at work was minimal. All three respondents who reported seizures at work were later interviewed. One interviewee described his handling of a tonic-clonic seizure, as follows: he was coming to the end of an important meeting where he had made a presentation when he got an aura of a seizure; he had time to excuse himself from the meeting, alert colleagues and locate an office where he could have the seizure undisturbed. Although it was unusual to leave the meeting early, no disruption of the proceedings had occurred.

The second interviewee who had seizures at work said that he had had several temporal lobe seizures in the office and that the most disruption these caused was a temporary lack of concentration on what was being said. Although these had occurred from time to time, no-one had mentioned them and he doubted that anyone had noticed. He thought they were most problematic if they occurred whilst he was on the phone. He overcame the problem by asking to ring back later. The third interviewee said that seizures had occurred quite often, always tonic-clonic, and usually without warning. She believed that work disruption was minimal, although her recovery time after a seizure was quite long and she had often had to go home after an attack. Her work colleagues were all aware of what needed to be done, and there was, according to her report, very little fuss.

A number of issues established by the literature review were reinforced by the pilot study. The main points that emerged were as follows:-

1. The group of people with epilepsy employed in BP is unusual in that it includes a number of technical and managerial staff who are not normally found in a study of epilepsy. This reflects the composition of the workforce at BP, but also suggests that these posts are obtainable by people with epilepsy.
2. The occurrence of seizures in the last 24 months was observed to occur significantly more frequently in clerical/manual work. The possibility that managerial or technical positions are unlikely to be obtained while seizures are not fully under control is therefore suggested.
3. Actual examples of stigma at work were not recalled by most of the interviewees, although incidents outside of work could be recalled. In the one case where stigma appeared to have occurred, attention was drawn to managers' versus colleagues' reactions.

4. According to the respondents' reports, there was no disruption caused by seizures at work. Part of the reasons for this may have been the type of seizure and the high rate of seizure warnings (auras).

5. A major need was for more information or employment advice on how employees would be treated by the organisation. The problem was expressed in the ambiguity of restrictions, for instance whether they would be allowed to work abroad and whether they were considered to be disabled or not.

8.7 Evaluation of the pilot study

The pilot study demonstrated that employees were prepared to discuss issues related to their employment. It also showed an acceptable response rate to the self-completion questionnaire. The questionnaire data were confirmed by the interviews although it was noted that objective measures of work performance and sickness absence were required for further analysis to be undertaken.

CHAPTER NINE

CIVIL SERVICE STUDY

Contents

9.1	Introduction
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9.1 Introduction

The Civil Service provided the opportunity to survey two populations of working people with epilepsy. The first group were recent recruits to the service. The second group were employees who had been referred to the Occupational Health Service by Management due to a health problem or need for clarification of restrictions. This group provided an example of people likely to be encountered as 'having a problem'.

The aims of this chapter are to describe two populations of employees with epilepsy and explore the problems they encountered at work. This was done by testing the biopsychosocial framework developed in Chapter Seven.

The study at the Civil Service was a two-year research project funded by the Health and Safety Executive. The Civil Service was an ideal study organisation for a number of reasons:

- 1) there was support throughout the organisation;
- 2) the organisation was large enough to guarantee a representative sample of people with epilepsy.

Epilepsy was defined as the occurrence of a seizure in the previous two years or current use of anti-convulsant medication.

9.2. Method

Potential respondents were identified with the assistance of the Civil Service's Medical Advisers in each region across the UK. The criteria for inclusion in the survey were as follows:-

1. Employed by the Civil Service;
2. Resident in the United Kingdom;
3. A diagnosis of epilepsy;
4. Referred to the Occupational Health Dept.;
5. Referred between July 1985 and March 1987.

Referrals during the study period were divided into two groups:

- 1) employees with epilepsy recently recruited to the Civil Service. These will be referred to as 'recruitment referrals' (RR); and described in section 9.3;
- 2) employees referred by management because of the need for advice. These will be referred to as 'management referrals' (MR) and described in section 9.4.

9.2.1 Referral process

In order to minimise the amount of work involved in notification of a referral, medical advisers were sent specially designed forms to complete for each referral.

The Medical Adviser was given the option of sending a copy of the Civil Service form E55 or G201 instead of completing the form. The E55/G201 contains information on the employee's date of birth, grade, department, establishment, sickness absence and registration of disability.

The initial request for referrals made to the regional Medical Advisers was made in July 1985. This was followed by further requests at four-monthly intervals. On each occasion a brief

report on the progress of the study was provided with the request. In March 1987, a final letter was sent thanking the Advisers for their help and informing them that no further referrals were required.

9.2.2 Documentation

The following documents were available to the Civil Service Occupational Health team:

- Medical reports - Included with the personnel records. Reports from the employee's GP or hospital doctor, or from the Civil Service list of Local Medical Officers (LMOs) or consultant referees.
- Health Declaration Form - This form is completed by all employees at the time of recruitment. It lists details of any medical condition.
- Welfare reports - This was available for only a few respondents. It is completed by a Civil Service Welfare Officer who may be called to make an assessment of the employee if a health problem arises during employment.
- Sickness Absence Record - Indicates time absent from work, reasons for absence.
- Annual (or probationary) Report - Completed by the employee's immediate supervisor in conjunction with higher management. The details are agreed with the employee during an annual interview. This report contains information concerning work performance and prospects for promotion; recommendations for improvement and comments about the employee.
- Minutes written by Personnel Officers - This would include correspondence between managers and the medical service. It would also include details of warnings for poor performance or unsatisfactory behaviour.

9.2.3 The Postal Questionnaire

In addition to the information obtained from the above documents, referred employees and recruits were also asked to complete a personal questionnaire, a copy of which can be found in Appendix 1. The questionnaire consisted of three sections:

- a description of the epilepsy symptoms;
- a description of their social situation;
- a description of their employment history and their current employment situation.

Fixed format (multiple choice) questions were used throughout the questionnaire in order to make completion as easy as possible. Two standard instruments, based entirely on multiple choice questions, were included in the questionnaire:

- Social Support Questionnaire (Corney & Clare, 1985)
- Job Diagnostic Survey (Hackman & Oldham, 1972).

The Social Support Questionnaire is further described in Appendix 2.

The job diagnostic questionnaire was intended to be used to make a judgement on the employment value given to people with epilepsy at work.

However, the data from this was not found useful, as a British norm could not be identified. Analyses based on this have not been included.

9.2.4 Contacting potential respondents

9.2.4.1 Recruitment referrals (RR)

Contact with referred recruits was not made until at least three months after appointment. This gave time for the potential respondent to settle into the post. The longest time between data collection and starting employment was 18 months, the mean period of tenure was 12 months. Initial contact took the form of a preliminary letter informing them that their case had been referred to the Medical Adviser. The aims of the research study were explained and they were told that a questionnaire would be sent to them during the next few weeks.

9.2.4.2 Management referrals (MR)

In the case of management referred employees, a standard letter was sent to their personnel officer, asking them to inform the employee about the study. A draft of a suitable letter was sent to the personnel officer, with the suggestion that they might wish to tailor the letter to their individual circumstances.

The personnel officer was also asked to confirm, on a slip, that they had written to the employee. Upon receipt of the slip a questionnaire was despatched to the employee's home address.

9.2.5 The total sample for the Civil Service

The Medical Advisers reported 345 cases. However, 37 recruitment referrals did not subsequently take up an appointment; this left 219 recruitment and 89 management referrals. There were ten management referrals whom the personnel department did not want to follow-up. In nine of these cases the reason given was that the individual was very sensitive to any mention of epilepsy and would react badly to being asked to complete a questionnaire. In the tenth case the individual was undergoing disciplinary action and it was felt that contact could prejudice the proceedings. It was established that these proceedings were not related to epilepsy. The medical and occupational characteristics of these ten referrals were not fundamentally different from other referrals (see 9.2.6.2).

Excluding the ten mentioned above, questionnaires were sent to 298 potential respondents; where these were not returned, two reminder letters were sent after a period of one and two months. There

were 148 postal questionnaires returned from recruitment respondents and 45 questionnaires returned from management referral respondents.

Table 9.0 Civil Service respondents

	Referrals	Respondents	Response rate
Recruitment (RR)	219	148	68%
Management (MR)	89	45	51%
Total	<u>308</u>	<u>193</u>	<u>63%</u>

9.2.6 Representativeness of sample

The representativeness of the survey samples was examined using data obtained from the medical and personnel records. The tables below compare the available data taken from the records of respondents against those taken from the records on the total population. A Kolmogorov-Smirnov test was used where the variable under consideration has a continuous distribution and a chi square (X^2) goodness of fit test (one sample) was used for categorical data. The sample distribution is compared against the expected distribution based on the actual population. In the tables below the total and sample distributions are shown. An alpha of 0.10 is chosen to increase confidence in avoiding a type 2 error (i.e. failing to reject the null hypothesis of no difference when it is in

fact false) and thus increasing the power of the test (p247. Hayes, 1981). One variable in the recruitment study (seizures at work) was not amenable to statistical analysis; differences between the referrals and the respondents on all other variables are non-significant (NS); the null hypothesis, therefore, cannot be rejected.

9.2.6.1 Recruitment population

The following tables show the total recruitment referral population related to the sub-set of respondents. Statistical comparisons are made between the observed and expected frequencies given the known population distribution.

Table 9.1.1a Age range

	Referrals (n=219)		Respondents (n=148)	
17 - 20	50	23%	39	26%
21 - 30	121	55%	74	50%
31 - 50	26	12%	16	11%
51 - 60	22	10%	19	13%
Mean age	27 years		27 years	
Standard deviation	8 years		9 years	
K-S D=0.0338				
Critical value for $\alpha=0.10$		$= \frac{1.22}{\sqrt{148}}$	$=0.10$	NS

Table 9.1.1b Sex

	Referrals (n=219)		Respondents (n=148)	
Male	103	47%	73	49%
Female	116	53%	75	51%
minEF=70	df=1	$X^2=0.24$	p>0.8 NS	

Table 9.1.1c Marital status

	Referrals (n=204)		Respondents (n=148)	
Single	155	76%	107	72%
Married	49	24%	41	28%
minEF=36	df=1	$X^2=0.918$	p>0.3 NS	

Table 9.1.1d Occupational grade

	Referrals (n=219)		Respondents (n=148)	
Manual work	18	8%	13	9%
Clerical assistant	144	66%	92	62%
Clerical officer	46	21%	33	22%
Executive officer	11	5%	10	7%
minEF=7	df=3	$X^2=1.865$	p>0.5 NS	

Table 9.1.1e Department

	Referrals (n=219)		Respondents (n=148)	
DHSS	46	21%	31	21%
Inland revenue	28	13%	15	10%
MoD	33	15%	24	16%
Employment	18	8%	15	10%
Other	94	43%	63	43%
minEF=12	df=4	$X^2=1.789$	p>0.7 NS	

Table 9.1.1f Seizure type

	Referrals (n=168)		Respondents (n=143)	
Including generalised	124	74%	102	77%
Other	44	26%	41	29%
minEF=37	df=1	$X^2=0.58$	p>0.3 NS	

Table 9.1.1g Seizures in previous 12 months

	Referrals (n=193)		Respondents (n=148)	
Seizures	93	48%	74	50%
None	100	52%	74	50%
minEF=71	df=1	X ² =0.24	p>0.8 NS	

Table 9.1.1h Seizures at work

	Referrals (n=193)		Respondents (n=148)	
Seizures	2	1%	0	0%
None	161	99%	148	100%

minEF=1.48 df=1

Comparison to Chi square distribution not
calculated, minimum expected in one cell below
five.

Comparison to normal distribution by Binomial test
not calculated. Npq=1.97 below recommended minimum
of 9 (p43; Siegel & Castellan, 1988).

9.2.6.2

Management population

As above, the representativeness of the management sample is compared with the expected frequencies based on the total population.

Table 9.1.2a Age range

	Referrals (n=89)		Respondents (n=45)	
18 - 20	2	2%	1	2%
21 - 30	31	35%	14	31%
31 - 50	44	49%	22	49%
51 - 60	12	14%	8	18%
Mean age	37 years		37 years	
Standard deviation	5 years		5 years	
K-S D=0.044				
Critical value for $\alpha=0.1$	$= \frac{1.22}{\sqrt{45}}$		=0.18	NS

Table 9.1.2b Sex

	Referrals (n=89)		Respondents (n=45)	
Male	54	61%	30	66%
Female	35	39%	15	33%
minEF=18	df=1	$X^2=0.833$	p>0.3 NS	

Table 9.1.2c Marital status

	Referrals (n=89)		Respondents (n=45)	
Single	55	62%	27	60%
Married	34	38%	18	40%
minEF=17	df=1	$X^2=0.095$	p>0.7 NS	

Table 9.1.2d Occupational grade

	Referrals (n=89)		Respondents (n=45)	
Manual work	24	27%	12	27%
Clerical assistant	30	34%	10	22%
Clerical officer	25	28%	17	38%
Executive officer	10	11%	6	13%
minEF=5	df=3	$X^2=3.097$	p>0.3 NS	

Table 9.1.2e Department

	Referrals (n=89)		Respondents (n=45)	
DHSS	16	18%	8	18%
Inland revenue	14	16%	6	13%
MoD	13	15%	6	13%
Other	46	52%	25	56%
minEF=7	df=3	$X^2=0.459$	p>0.9 NS	

Table 9.1.2f Length of service

	Referrals (n=89)		Respondents (n=45)	
Less than 2 years	38	43%	20	45%
3 to 5 years	28	31%	15	33%
Over 6 years	23	26%	10	22%
minEF=12	df=2	$X^2=0.439$	p>0.8 NS	

Table 9.1.2g Seizure type

	Referrals (n=70)		Respondents (n=42)	
Including generalised	62	88%	37	88%
Other	8	12%	5	12%
minEF=5	df=1	$X^2=0.0$	p>0.9 NS	

Table 9.1.2h Seizures in previous 12 months

	Referrals (n=71)		Respondents (n=45)	
Seizures	55	77%	31	69%
None	16	23%	14	31%
minEF=10	df=1	$X^2=1.67$	p>0.10 NS	

Table 9.1.2i Seizures at work

	Referrals (n=70)		Respondents (n=45)	
Seizures	38	54%	23	51%
None	32	46%	22	49%
minEF=21	df=1	X ² =0.15	p=0.7 NS	

9.2.7 Validity and reliability of the
questionnaire data

Personnel and medical records permitted validity of questionnaire data to be checked on three medical variables: seizure type; seizure occurrence; and seizures at work. The Senior Occupational Advisor determined that the questionnaire response was sufficiently accurate to be considered valid.

Ten respondents were also randomly chosen for interview. The questionnaire format was used as an interview schedule. The data obtained was compared with the data provided on the self-completion questionnaire and from the reports. The interview responses invariably confirmed the questionnaire data, therefore the latter were taken as a reliable picture of the respondent's circumstances.

9.3 Recruitment referral respondents

9.3.1 Demographic characteristics

The age range of the recruitment respondents was from 17 to 60 years, with the mean age being 27.03 years and a standard deviation of 9.6 years. There was a similar proportion of recruits from each sex, with 75 (51%) female and 73 (49%) male. More than half of the respondents were single (102 respondents, 69%). Only three respondents (2%) were divorced or separated. From the application forms it was noted that 51 respondents (34%) were registered with the job centre as disabled.

Respondents had been recruited nationally. The table below shows the geographical areas from which they were drawn.

<u>Table 9.2 Location of respondents (RR)</u>		
	<u>Frequencies</u>	<u>%</u>
London	67	45
South	26	18
Midlands	30	20
North	10	7
Scotland	12	8
Northern Ireland	<u>3</u>	2
	148	

Respondents were drawn from twenty five departments. Half of the respondents were drawn from the four largest Civil Service departments.

<u>Table 9.3 Department (RR)</u>		
Department	Frequencies	%
DHSS	31	21
Inland Revenue	15	10
MOD	23	16
Employment	<u>15</u>	<u>10</u>
	84	57
21 other departments	<u>64</u>	<u>43</u>
	148	100

9.3.1.1 Education

Seventy three respondents (49%) had completed further education and a further 18 respondents (12%) had been to University and Polytechnic. (See 9.3.3.19 for responses concerning disrupted education.)

<u>Table 9.4 Education level completed (RR)</u>		
	Frequencies	%
Education level:		
Below O' levels	20	14
6th form	24	16
Apprenticeships or skills courses	14	9
Further Education College	72	49
Polytechnic or University	<u>18</u>	<u>12</u>
	148	

9.3.1.2 Family members with epilepsy

Respondents were also asked if they had family members with epilepsy. There were thirty-one recruitment respondents (21%) who had family members with epilepsy.

Warnings for poor performance had been issued to 7% of the group, which the Occupational Health Advisor considered to be within expectations for a random sample of recruits. Very high sickness absence was found in one respondent (308 days), where epilepsy had started recently. The remaining respondents did not have above average sickness absence. There was no indication, in the records or in the questionnaire response, of employment problems identified by employees.

Over half of the sample (53%) had been unemployed for more than three months. Within this figure there are 35 respondents (24%) who said that they had been unemployed for over one year. Respondents had been unemployed for a mean of four months in the twenty-four months prior to joining the Civil Service.

Table 9.5 Unemployment in the previous year (RR)

	Frequencies	%
Less than 3 months	28	19
Over 3 months	79	53
Never Unemployed	40	27
Not answered	<u>1</u>	1
	148	

9.3.2.1 Stigma at work

There was no indication from the personnel records of attitude problems with other members of staff. (See 9.3.3.18 for further details).

9.3.2.2 Employment advice

Apart from the initial requirement to refer employees to the Occupational Health Department, management did not request further information on the employment of this group.

9.3.3 Testing the biopsychosocial framework

The following sub-section is divided into the elements of the biopsychosocial framework which was discussed in Chapter Seven (see table 7.1). Measurement of sickness absence and work performance were based on records maintained by management and personnel.

Sickness absence is judged in terms of the mean number of days sickness absence in the twelve months prior to examination of records or that part of the twelve months the respondent was in employment with the Civil Service. Two measures are identified: total days sickness absence and absence related specifically to epilepsy.

Work performance ratings from the Annual reports were not available for 55% of the sample. This was due to respondents not being employed for a full year at the time of data collection, being in grades which did not require annual reporting and delays in annual reports being completed. The Occupational Health Advisor established that the delay in completion of the Annual reports was not related to the respondents having epilepsy. A measure of poor performance was available from the records which showed if a warning for poor performance had been issued by the management.

This is a criterion-based measure and reflects a persistent or major problem with work performance as judged by the line manager. A score for warnings of poor performance was available for all respondents and this was used as an good indicator of problems occurring at work.

The identification of restrictions placed on the work of the respondents was made from the personnel records by the Occupational Health Physician.

A Pearsons correlation coefficient was calculated for the correlation of age of onset with sickness absence. In the remaining analyses, statistical measures of independence were conducted. Where the data were of at least interval level a t-test was used with a conventional alpha of 0.05. As the sample sizes are nearly always different attention will be paid to the t-test assumption of homogeneity of variance and therefore an F-test is carried out before each t-test. Where the assumption of homogeneity of variance cannot be rejected ($p > 0.05$) the pooled variance is used for the calculation of the t-test; where homogeneity cannot be demonstrated, separate standard errors are computed and the corrected number of degrees of freedom is shown. Where only categorical data

were available a non-parametric test was used. As the sample size is large, calculation of the exact probabilities becomes cumbersome, therefore, the chi-square approximation is used corrected for continuity. The analysis of the chi-square will adopt the current and widely endorsed convention that a minimum expected frequency of five is expected in each cell where there is one degree of freedom (p 123; Siegel & Castellan, 1988). Minimum expected frequency (minEF) values will be included in the text and tables. Not all the variables were amenable to statistical analysis because too few respondents were found in some categories.

Dependent variables

9.3.3.1 Job type

The mean length of tenure for this group was twelve months. Employment grades are shown below. There were no recruits at the level above Executive Officer in this group.

Table 9.6 Employment Grade (RR)

	Frequencies	%
Manual worker	11	7
Senior manual worker	2	1
Clerical Assistant	93	63
Clerical Officer	32	22
Executive Officer	<u>10</u>	7
	148	

9.3.3.2 Work performance

Work performance could not be taken from the ratings in the annual reports because in most cases (74%) these had not been completed at the time of data collection. However, from an examination of the personnel records, the number of warnings issued for poor performance was collected. The warnings are recorded separately from the annual report and can be used as an indicator of work performance. There were ten respondents (7%) issued with warnings due to poor performance.

9.3.3.3 Sickness absence

There was a mean of 2.77 days (SD = 9.32; skew = 5.75) lost due to sickness absence in this group in the previous 12 months. This included a mean of 0.78 days (SD = 4.76; skew = 8.91) due to epilepsy. In both cases the median value was no days taken. Total sickness absence was judged by the senior Civil Service Occupational Health Advisor to be equivalent to sickness absence levels for a general recruitment sample.

9.3.3.4 Shift work

None of the subjects reported that they were doing shift work.

9.3.3.5 Restrictions on employment

From the personnel records it was found that eight respondents (5%) were restricted in their working activities following recruitment. These restrictions were all related to heights and dangerous machinery; they were recorded in personnel records without reference to the criteria upon which they had been set or stated periods for review. None of these eight respondents had received warnings of poor work performance. As the expected frequency in one of the cells is below one, a chi-square test will not be computed. The imposition of restrictions was

not related to total sickness absence ($F=1.66$
 $p=0.493$; pooled estimate variance $t=0.21$ $df=125$
 $p=0.835$) or epilepsy-related absence ($F=55.98$
 $p=0.000$; separate estimate variance $t=1.27$
 $df=86.31$ $p=0.209$).

Table 9.7a Formal restrictions and total sickness absence (RR)

Restrictions	N	Mean days	SD
Yes	8	3.88	7.88
No	119	3.11	10.16
NS			

Table 9.7b Formal restrictions and epilepsy related sickness absence (RR)

Restrictions	N	Mean days	SD
Yes	8	0.25	0.71
No	119	0.94	5.29
NS			

Respondents also indicated if they restricted their own activities in relation to work due to the epilepsy. Sixty-one respondents (41%) said that they would restrict their employment. This group did not take significantly more sickness absence than those not imposing self-restrictions (Total sickness absence - $F=2.49$ $p=0.000$; separate estimate variance $t=1.31$ $df=93.37$ $p=0.194$)

(Epilepsy-related absence - $F=2.42$ $p=0.000$;
separate estimate variance $t=0.38$ $df=145.02$
 $p=0.702$).

9.3.3.6 Accidents at work

There were no recorded accidents at work.

Independent variables

9.3.3.7 Seizure type

A note of the seizure type was found in most of the medical records. The highest incidence of seizure type given in the medical records, was a combination of tonic-clonic and absence seizures, followed by tonic-clonic on their own. This was consistent with the questionnaire response which showed that 100 respondents had seizures resulting in falling, roughly consistent with the tonic-clonic and mixed seizure categories. A combined category of 'including generalised' seizures was created in order for comparisons to be made with other studies where available data did not supply an exact breakdown. Chi square not calculated for warnings of poor performance ($\min EF=2.87$); nor for formal restrictions ($\min EF=2.01$).

Table 9.8a Type of seizures related to warnings
of poor performance and restrictions (RR)

	n	%	Poor perf.	Restrictions
Including			%	%
generalised	102	71	7	6
Other	41	28	3	1
			7	2
			minEF=2.87	minEF2.01

No statistical relationship was found between type of seizure and total sickness absence ($F=1.02$, $p=0.985$; pooled variance estimate $t=0.11$ $df=141$ $p=0.91$); or epilepsy-related absence ($F=8.43$, $p=0.000$; separate variance estimate $t=0.64$ $df=43.86$ $p=0.527$).

Table 9.8b Type of seizure related to total
sickness absence (RR)

	N	Mean days	SD
Including			
generalised	102	2.93	9.52
Other	41	2.73	9.45
		NS	

Table 9.8c Type of seizure and epilepsy-related
sickness absence (RR)

	N	Mean days	SD
Including			
generalised	102	0.58	2.75
Other	41	1.39	7.97
		NS	

Fourteen respondents said that they had seizures only during sleep. No statistical relationship was found between seizures occurring only during sleep and total sickness absence ($F=3.23$, $p=0.001$; separate variance estimate $t=0.55$ $df=13.86$ $p=0.59$); or epilepsy-related absence ($F=31.25$, $p=0.000$; separate variance estimate $t=0.91$ $df=13.09$ $p=0.379$). No warnings of poor work performance were issued to respondents who had seizures only during their sleep. (X^2 not calculated $minEF=0.95$). Formal restrictions were not imposed on respondents having seizures only during sleep (X^2 not calculated; $minEF=0.64$).

9.3.3.8 Incidence of seizures

Half of the sample had had seizures within the previous twelve months. The median seizure frequency was one seizure every six months, although some respondents had seizures more frequently than once per week. The warnings due to poor performance fail to demonstrate a significant difference in terms of seizure incidence ($X^2=2.68$ $df=1$ $p=0.102$ $minEF=5$). No significant difference is found in terms of restrictions ($X^2=0.828$ $df=1$ $p>0.3$ $minEF=5$).

Table 9.9a Seizures in previous 12 months
related to restrictions and poor performance (RR)

	n	%	Poor perf.		Restrictions	
				%		%
Seizures	74	50	2	3	3	4
None	74	50	8	11	5	7
			NS		NS	

Respondents having seizures took significantly more total sickness absence than respondents not having seizures ($F=12.01$ $p=0.000$; separate estimate variance $t=2.06$ $df=85.07$ $p=0.043$). This relationship, however, does not hold true for sickness absence related to epilepsy, where there is no significant difference between respondents having seizures and those not having seizures ($F=663.84$ $p=0.000$; separate estimate variance $t=1.92$ $df=73.33$ $p=0.059$).

Table 9.9b Incidence of seizures related to
total sickness absence (RR)

	N	Mean days	SD
Seizures occurring	74	4.34	12.53
None last year	74	1.22	3.62
		$p=0.043$	

Table 9.9c Incidence of seizures and epilepsy
related sickness absence (RR)

	N	Mean days	SD
Seizures occurring	74	1.53	6.66
None last year	74	0.04	0.26
		NS	

9.3.3.9 Increase in seizures

There was one respondent who had recent onset of epilepsy. This respondent had taken very lengthy sickness absence. For further data on this respondent see section 9.3.3.16. No indication was given by the remaining respondents that they had experienced a recent increase in seizure activity.

9.3.3.10 Warnings of a seizure (aura)

Thirty-seven respondents (25%) were always aware of warnings of an impending seizure on a regular basis which allowed them to take action to avoid accidents or embarrassment. There were also fifty-four respondents (36%) who said that they never received an aura. As the responses tend to

fall at the extremes of the scale and in order to increase the chances of finding a difference if one exists, the two extremes of the scale are compared. However, to avoid falsely rejecting the null hypothesis (type 1 error) an alpha of 0.01 is chosen (p246. Hayes, 1981). If these two extremes of the range are compared, it is found that there was no difference in terms of sickness absence (total sickness absence $F=4.33$ $p=0.000$; separate variance estimate $t=0.82$ $df=81.16$ $p=0.415$; epilepsy-related absence $F=4.37$ $p=0.000$; separate variance estimate $t=0.53$ $df=81.02$ $p=0.596$). Comparison of aura to warnings of poor work performance and restrictions cannot be made as two expected frequencies are below five.

9.3.3.11 Recovery time

A range of recovery times were given, from a few seconds to 24 hours. The range is divided into two, using half an hour of lost time as the division, since we can assume that the loss of half an hour of work time can easily be made up (this being equivalent to time taken for a tea break). It is found that there were seventy-two respondents (49%) taking less than half an hour to recover and seventy-three (49%) taking longer (three respondents were unable to answer this question). There was no difference in terms of sickness absence (total sickness absence $F=3.94$ $p=0.000$; separate variance estimate $t=0.49$ $df=104.53$ $p=0.626$; epilepsy $F=7.92$ $p=0.000$; separate variance estimate $t=0.67$ $df=88.44$ $p=0.507$). A comparison with poor work performance not calculated ($\min EF=4.97$). A comparison with restrictions could not be made due to two expected frequencies below five.

9.3.3.12 Coincidental disorders

The medical condition was judged from the medical files and from the replies to the questionnaire. Thirty-two respondents (22%) said that they had had a serious physical illness, unrelated to the epilepsy, in the previous 5 years. One of the respondents in the sub-group with a prior physical illness had received warnings for poor performance (X^2 not calculated, $\text{minEF}=2.24$). Three respondents had formal restrictions placed on them (X^2 not calculated, $\text{minEF}=1.76$). There was no relationship between this variable and total sickness absence ($F=2.17$ $p=0.014$; pooled variance estimate $t=0.05$ $df=145$ $p=0.962$) nor epilepsy-related sickness absence ($F=2.7$ $p=0.002$; separate variance estimate $t=0.032$ $df=86.51$ $p=0.747$).

On the questionnaire 134 respondents (91%) said that their health was good or excellent. There was no difference between respondents reporting good or poor health in terms of sickness absence (total sickness absence $F=1.12$ $p=0.906$; pooled variance estimate $t=0.51$ $df=146$ $p=0.614$; epilepsy-related absence $F=1.21$ $p=0.577$; pooled variance estimate $t=0.54$ $df=146$ $p=0.588$). No respondents with poor health received warnings of poor work performance or formal restrictions.

9.3.3.13 Factors precipitating a seizures

There was no reference in the records to precipitating events and no reference to stress as a factor. (It should be noted that full records were available only for the period of employment.) However, this issue was examined in the questionnaire with both fixed response categories and open format. Comparisons with warnings of poor performance and restrictions could not be made as all calculations involved minimum frequencies of less than five.

Table 9.10a Precipitating factors

	n	%
<u>Fixed response</u>		
Alcohol	14	9
TV, flashing lights	39	26
Lack of sleep	42	29
Forgetting drugs	47	32
Stress at work	42	16
<u>Open response</u>		
Waking	3	2
Excitement	1	<1
Periods	6	4
Too hot	1	<1
Too cold	1	<1
Physical exertion	3	2
Hormonal problems	4	3
Loud noise	2	1
Lack of food	1	<1

Table 9.10b Fixed response factors related to
total sickness absence

	F=	p=	t=	df=	p=
Alcohol	9.99	0.00	0.89	13.27	0.39
TV,flashing	5.48	0.00	1.97	43.06	0.06
Lack of sleep	15.07	0.00	1.75	43.17	0.09
Forgetting drugs	3.25	0.00	0.89	59.54	0.38
Stress at work	15.88	0.00	1.98	43.06	0.05**

** Significant difference

Table 9.10c Fixed response factors and
epilepsy-related sickness absence

	F=	p=	t=	df=	p=
Alcohol	189.13	0.00	1.60	143.05	0.11
TV,flashing	1.34	0.30	0.45	146	0.66
Lack of sleep	18.02	0.00	1.10	42.74	0.28
Forgetting drugs	1.71	0.04	0.05	114.87	0.62
Stress at work	20.45	0.00	1.22	42.60	0.23

When these factors are related to the dependent variables it is found that stress is the only factor which demonstrates a relationship.

9.3.3.13.1 Stress precipitating seizures

There were forty-two respondents (28%) indicated that stress was seen as a precipitatory factor to seizures. Respondents reporting stress as a precipitatory factor were not likely to take more epilepsy-related sickness absence (F=20.45 p=0.000; separate variance estimate t=1.22 df=42.6 p=0.228). However, they were found to take more total sickness absence (F=15.88 p=0.000; separate variance estimate t=1.98 df=43.06

p=0.054). Only one respondent said that they would avoid stress because of their epilepsy.

Table 9.10c Stress related to warnings of poor performance and restrictions						
	n	%	Poor perf.		Restrictions	
				%		%
Stress	42	28	3	7	6	14
Not stress	106	72	7	7	2	2
			minEF=2.84		minEF=2.21	

9.3.3.14 Drug side-effects

Respondents referred to previous side-effects of medication, but no respondents indicated they had experienced side-effects within the last two years. Respondents were also asked if they were satisfied with their present medication. Twelve respondents said that they were not satisfied. This group had not received any warnings due to poor performance. Only one respondent in the unsatisfied group was given formal restrictions. A comparison with the satisfied group on this issue could not be calculated (minEF=0.752). However, a difference was detected in the total sickness absence figures (F=51.07 p=0.000; separate estimate variance t=2.34 df=11.04 p=0.039), although this relationship was not found for epilepsy-related sickness absence (F=383.34 p=0.000; separate estimate variance t=1.63 df=11.01 p=0.131).

Table 9.11a Satisfaction with medication
related to total sickness absence (RR)

Satisfied with medication	N	Mean days	SD
Yes	123	1.32	3.64
No	12	18.92	26.03
p=0.039			

Table 9.11b Satisfaction with medication
and epilepsy-related sickness absence (RR)

Satisfied with medication	N	Mean days	SD
Yes	123	0.19	0.79
No	12	7.50	15.52
NS			

9.3.3.15 Age of onset of epilepsy

One hundred and ten respondents (74%) had onset of epilepsy prior to the age of seventeen years. The median age of onset was 14 years. A Pearsons correlation coefficient was calculated for comparison with sickness absence variables. Total sickness absence was not significantly associated with age of onset ($r=0.085$); neither was epilepsy absence ($r=0.189$). These figures show that very little of the variance in sickness absence can be explained by age of onset of epilepsy.

Table 9.12 Age of onset of Epilepsy (RR)

Age onset	N	<u>Mean days sick:-</u>	
		Total sickness	Epilepsy only
1 - 10	39	4.56	1.66
11 - 16	71	6.67	0.78
17 - 30	29	4.14	0.79
31 up	9	20.67*	17.00*
Mean	14.4	2.77	0.78
SD	9	9.32	4.76
Skewness		5.75	8.91
Median	14	0.00	0.00
Correlation		$r=0.085$	$r=0.189$

* Note. The sickness absence distribution is skewed by the presence of one subject who took 58 days total sickness absence which included 51 days related to epilepsy. See section 9.3.3.16.

In order to facilitate statistical comparison with the other dependent variables onset was divided into two groups, below sixteen years and above 16

years. However, a comparison with poor work performance could not be calculated (minEF=2.57), nor restrictions (minEF=1.95).

9.3.3.16 Onset after employment

One respondent had onset of epilepsy after starting work with the Civil Service. This respondent took 51 days sickness absence due to epilepsy. There was no indication from the personnel records that this person was judged as having poor work-performance.

9.3.3.17 Behaviour at work

Personnel records were monitored for evidence of poor or anti-social behaviour at work. None of the respondents received warnings due to poor or anti-social behaviour.

9.3.3.18 Attitudes of managers and co-workers

Most respondents indicated that their managers were aware of their epilepsy (n=120 81%); however, in a third of cases co-workers were unaware that they had epilepsy (n=51 33%). Only three respondents (2%) felt that their managers were fearful of epilepsy, none of these have been given formal restrictions. In six cases (4%) co-workers were seen as fearful. Two of the group identifying fear of epilepsy in co-workers had been issued

with a warning for poor performance ($\text{minEF}=0.41$ therefore X^2 not calculated). None had formal restrictions.

9.3.3.19 Disrupted education

Respondents were asked if they felt that epilepsy had disrupted their education. Forty respondents (27%) felt that their education had been affected.

9.3.3.20 Social Support problems

Results from the social support questionnaire did not indicate that this group had major problems. Six respondents (4%) indicated that they had a 'marked' problem. A further 46 respondents (31%) identified minor problems. This is a total of 52 respondents (35%) with some difficulties. Problems were recorded in the areas of finance (14%), dealing with relatives (13%), social contacts (10%) and work (8%).

Respondents reporting social support problems were not likely to take more total sickness absence ($F=1.3$ $p=0.272$; pooled variance estimate $t=1.25$ $df=146$ $p=0.213$;) or epilepsy-related absence ($F=407.85$ $p=0.000$; separate variance estimate $t=1.85$ $df=51.14$ $p=0.07$). Comparisons of this

variable with warnings of poor performance ($n=3$) could not be made ($\text{minEF}=3.51$) nor with formal restrictions ($\text{minEF}=2.84$).

9.3.3.21 Seizures at work

No seizures at work had occurred in this group since joining the Civil Service. Sixty-three respondents (43%) had had seizures at work in previous employment. This group was not found to take more total sickness absence ($F=2.14$ $p=0.001$; separate estimate variance $t=0.52$ $df=103.26$ $p=0.6$) or more epilepsy-related sickness absence ($F=2.59$ $p=0.000$; separate estimate variance $t=0.13$ $df=142.11$ $p=0.89$). Comparisons to this variable with warnings of poor performance could not be made ($\text{minEF}=4.26$) nor with formal restrictions ($\text{minEF}=3.40$).

9.3.3.22 Disruption due to seizures

No seizures at work had occurred since joining the Civil Service. In fourteen cases (10%), however, respondents had been injured during a seizure at work in the past.

9.3.4 Main findings

The main findings drawn from the recruitment study are as follows:

- # People with epilepsy were employed throughout the Civil Service.
- # Over 50% of the respondents had seizures in the previous 12 months.
- # There were no seizures recorded occurring at work since joining the Civil Service.
However, 43% of the sample had had seizures at work in the past.
- # Work performance was unrelated to seizure occurrence, seizure type or age of onset of epilepsy.
- # Total sickness absence was significantly related to occurrence of seizures.
- # Work performance was satisfactory in 93% of the sample.
- # A mean of three days total sickness absence and one day due to epilepsy were recorded for the previous twelve months.
- # Respondents dissatisfied with their medication took a significantly greater amount of total sickness absence.

- # Respondents identifying stress as a possible precipitator of seizures were significantly more restricted at work and took significantly more total sickness absence.
- # Over 95% of managers and colleagues were not seen as fearful of epilepsy by respondents.

9.4.0 Management referral respondents

Questionnaire responses were received from forty-five employees who were referred to the Civil Service Occupational Health Service on account of a problem arising in employment. For the type of problems see section 9.4.2.

Following medical review thirteen people (29%) were given early retirement due to ill-health. The remaining respondents were retained in employment.

9.4.1 Demographic characteristics

The age range of respondents was from 20 to 65 years. The mean age was 37.4 years with a standard deviation of 11.6 years and the median age was 35 years.

Table 9.13a	Age of respondents (MR)	
	Frequencies	%
18 - 20	1	2
21 - 30	14	31
31 - 40	13	29
41 - 50	9	20
51 - 60	7	16
61 - 65	<u>1</u>	2
	45	
Mean age	37	

Two thirds of the sample were male (30 respondents). Twenty-six respondents (58%) were single. The majority of the respondents came from

London or the South, which reflects the concentration of the Civil Service establishments within this area. Eight respondents (18%) were registered as disabled.

Table 9.13b Location of respondents (MR)

	Frequencies	%
London & Home Counties	15	33
South	11	24
Midlands	3	7
North	9	20
Scotland	6	13
Northern Ireland	<u>1</u>	2
	45	

Over half of the respondents came from the four largest departments - DHSS, Inland Revenue, MOD and Department of Employment.

	<u>Department</u>	
	Frequencies	%
DHSS	8	18
Inland Revenue	6	13
MOD	6	13
Employment	<u>3</u>	7
	23	
Other	22	49

There was a wide spread of educational attainment throughout the sample. The two largest groups of respondents are those who left school prior to O' levels and those who went on to further education after sixth Form. (See also 9.4.4.19.)

Table 9.13d Education Establishment Attended (MR)

	Employment respondents	
		%
Left school :-		
prior to O' levels	14	31
after 6th Form	<u>31</u>	69
	45	
Entered:-		
Apprenticeships		
or skills courses	6	13
Further Education College	15	33
Polytechnic or University	3	7
No further education	<u>21</u>	46
	45	

9.4.1.2 Family members with epilepsy

Respondents were also asked if they had family members with epilepsy. There were four management respondents (9%) who had family members with epilepsy.

9.4.2 Employment problems

All the respondents can be identified as having an employment problem that had led to their referral to the Occupational Health Service for advice. In 14 cases (31%) respondents had been referred due to excessive sickness absence, in five of these cases the respondent had also recently had the onset of epilepsy. In 12 cases (27%) referral was due to poor work performance. In the remaining 19 cases (42%) management referral was mainly concerned with review of the restrictions imposed upon the employee; in some cases the request for review had been generated by the employee themselves.

Early retirement was offered to thirteen employees, including all respondents with recent onset of epilepsy.

9.4.2.1 Stigma at work

From personnel reports it was found that ten managers mentioned the possible adverse effects of epilepsy on other members of staff and asked for advice from the Occupational Health Service. These requests were all related to occurrence of seizures at work. In some cases concern was expressed, not only about the direct effect of watching a seizure, but also the indirect effects of worry about a seizure occurring. Requests for training were made from line managers so that they could deal with this 'problem'. (See also 9.4.4.18.)

9.4.3.2 Employment advice

There were two main reasons for management requests for advice from the occupational health service during the study period. These were:

- 1) Departmental review of employment issues
 - * excessive sickness absence
 - * poor work performance
- 2) Departmental review of working conditions
 - * review of work restrictions

Referrals can be further broken down into referrals related exclusively to epilepsy (N=34) and referrals related to a number of conditions which included epilepsy (N=11). The frequency of referrals can be seen from the table below.

<u>Table 9.14 Reasons for referral (MR)</u>		
	Epilepsy only	Epilepsy plus other conditions
Sickness Absence	8	6
Work performance	7	5
Review of restrictions	19	-

The personnel reports showed a concern by the employees and managers for more adequate advice on the type of restrictions to be placed on people with active epilepsy. A number of personnel reports expressed the feeling that blanket restrictions like 'shouldn't work with dangerous machinery' were inadequate.

Requests for advice were also generated by employees. There was one example of this in this group. The employee, through his manager, requested clarification on how he would get appropriate experience for promotion if he was restricted in the areas where experience was required. In this case senior posts would not have been restricted but junior posts, within the

standard career path, required the performance of some tasks which were prohibited to this individual. This situation had not been resolved at the end of the study.

9.4.3 Testing the biopsychosocial framework

The following sub-section is divided into the elements of the biopsychosocial framework which was discussed in Chapter Seven (see page 174). The dependent variables used in the analysis were work performance, sickness absence and formal restrictions noted in the personnel records.

Gradings from the staff annual reports were taken but these were not available for eight respondents (18%) on grades where they are not completed on a regular basis and had not been completed for over a year for eight other respondents (18%). A more reliable measure of work performance, available for all respondents, was the issue of warnings for poor performance. This criterion-based indicator of performance is given upon managerial judgement where performance has been consistently low and gives an accurate picture of whether problems are occurring at work. Frequency of poor performance warnings will therefore be used as the work performance variable.

The figures for sickness absence given below are the mean number of days taken as sick leave in the twelve months prior to the analysis of the records. The two sets of figures relate to the total number of days absent and the number of days attributed to epilepsy.

A Pearsons correlation coefficient was calculated for the measure of association between age of onset and sickness absence. In the remaining analyses, statistical measures of independence were conducted. Where the data was of at least interval level a t-test was used; where only categorical data was available and it has been possible to calculate the exact probabilities, a Fisher exact test is used. Where this has not been possible a Chi square test has been used, the conventional criteria of expected frequencies above five is applied. An alpha of 0.05 was chosen unless otherwise stated.

Dependent variables

9.4.3.1 Type of job

Respondents were drawn from a range of occupations which included manual and clerical work, but there were no respondents found above Executive Officer grade.

Table 9.15	Job type	(MR)
	Frequencies	%
Manual worker	11	25
Senior manual worker	1	2
Clerical Assistant	10	22
Clerical Officer	17	38
Executive Officer	<u>6</u>	13
	45	

9.4.3.2 Work performance

Recent work performance data from the annual reports (less than 12 months old) were available on twenty-nine respondents. The distribution of work performance is close to a normal distribution with fourteen respondents (48%) judged as 'good' or better in terms of work performance by management and fifteen (52%) judged as 'fair' or below. It is noted that this does not correspond to the distribution for promotion prospects (recent rating n=25) which is heavily skewed towards the 'not fitted' end of the range. Sixteen

9.4.3.3 Sickness Absence

The range of epilepsy-related sickness absence was from no days absence for nineteen respondents to one subject with 308 days absence in the 18 month study period. The distribution is skewed by the presence of five respondents who have taken very lengthy sickness absence. The median absence rate is therefore the best indicator of the average for this group. The median for total sickness absence in twenty-nine days and for sickness absence related to epilepsy it is one day.

The longest sickness absence figures were recorded for respondents who had had recent onset of epilepsy. All respondents taking sickness absence over 31 days had active epilepsy with a seizure pattern which included generalised seizures.

Significantly greater amounts of total sickness absence were taken by the management referral sample than the recruitment sample ($F=59.55$ $p=0.000$, separate estimate variance $t=5.49$ $df=44.45$ $p=0.000$), and significantly greater amounts of epilepsy-related sickness absence ($F=161.17$ $p=0.000$, separate estimate variance $t=3.47$ $df=44.17$ $p=0.001$).

Table 9.17		Mean sickness absence		(MR)	
Days		Total sick- absence		Epilepsy related	
		Freq.	%	Freq.	%
None		4	9	19	42
1 - 5		10	22	8	18
6 - 10		1	2	2	4
11 - 20		4	9	2	4
21 - 30		5	11	1	2
31 & over		21	47	13	29
Mean		62 days		33 days	
Standard deviation		72		60	
Skewness		1.41		2.7	
Median		29 days		1 day	

9.4.3.4 Shift work

Five of the respondents did shift work. None of these had had seizures in the previous 24 months.

9.4.3.5 Restrictions on employment

9.4.3.5.1 Formal restrictions

From the personnel records, the Occupational Physician was able to determine if restrictions at work were placed upon an employee due to the diagnosis of epilepsy. The restrictions found covered four areas:

1. situations where help could be delayed;
2. hazardous working;
3. where a seizure might jeopardize security;
4. hazardous duties e.g. driving or using VDUs.

Formal restrictions were imposed on 42% of the group. The main restrictions for clerical grades were being prevented from working in areas where help would be delayed. The main restriction for manual grades was being prevented from working in areas considered to be dangerous. There were significantly more restrictions imposed on this sample than on the recruitment referral sample ($X^2=38.91$ $df=1$ $p<0.001$ $minEF=6.29$).

<u>Table 9.18 Formal restrictions (MR)</u>		
	Frequencies	%
Restrictions	19	42
No restrictions	<u>26</u>	58
	45	

The records which included memos between Occupational Health and Management did not give specific instructions on how restrictions were to be applied, nor did they give review dates or the criteria for lifting the restrictions. There was no difference between the number of warnings issued to those with formal restrictions to those who did not have formal restrictions (Fisher exact $p>0.288$). Imposition of restrictions was not related to total sickness absence ($F=2.27$ $p=0.077$;

pooled estimate variance $t=1.38$ $df=43$ $p=0.174$) or epilepsy-related absence ($F=5.98$ $p=0.000$; separate estimate variance $t=1.11$ $df=35.18$ $p=0.275$).

9.4.3.5.2 Self-imposed restrictions

Respondents were also asked if they would voluntarily avoid certain types of work activity due to difficulties with medication or fear of seizures. Twenty-one respondents (47%) said that would, ten of these were not given formal restriction by the Occupational Health Service.

Table 9.19a Formal and self restrictions

		<u>Formal restrictions</u>	
		Yes	No
<u>Self restrictions</u>	Yes	11	10
	No	8	16

Table 9.19b Voluntary restrictions (MR)

<u>Avoided due to epilepsy</u>	Frequencies	%(n=45)
Shift work	6	13
Dangerous machinery	12	27
Working alone	4	9
Working at heights	12	27
Working with a VDU	1	2
Working with chemicals	1	2
Overtime	1	2
Night work	1	2
Offices with fluorescent lighting	1	2

Thirty-nine separate restrictions were indicated by twenty-one respondents. There was no difference between this group and the other respondents on

sickness absence ratings (total sickness absence-
F=2.26 p=0.062; pooled estimate variance t=1.45
df=43 p=0.155); (epilepsy absence - F=2.74
p=0.022; separate estimate variance t=0.63 df=32
p=0.534).

There was no significant difference between the
management referral sample and the recruitment
sample on this variable ($\chi^2=0.42$ df=1 p>0.7
minEF=19.12).

9.4.3.6 Accidents at work

There was no indication of any accidents occurring
at work due to a seizure.

Independent variables

9.4.3.7 Type of seizure

Seizure type was assessed by analysis of the medical records available to the Occupational Health Staff and by reference to the questionnaire. However, the records were not sufficiently detailed to distinguish precisely the seizure pattern of individuals, therefore a category of 'including generalised' was used. This allowed greater confidence in the data and allows comparison to the other studies. Thirty seven respondents (88%) had experienced seizures which included generalised seizures at some time. This is a significantly higher proportion than the frequency of 71% including generalised seizures found in the recruitment sample ($X^2=4.88$ $df=1$ $p<0.05$ $minEF=10.44$).

The proportion of warnings of poor performance issued to respondents whose seizure pattern included generalised seizures was no different to that issued to other respondents (Fisher exact $p>0.44$). The number of respondents given restrictions was also not related to the type of seizure (Fisher exact $p>0.22$).

Table 9.20a Seizure pattern related to work performance and restrictions (MR)

Seizure pattern	N	Warnings poor perf.		Restrictions	
Including generalised	37	7	19%	17	46%
Other	5	1	25%	1	25%
		NS		NS	

It is shown that both the total level of sickness absence ($F=1.72$ $p=0.643$; pooled estimate variance $t=0.49$ $df=40$ $p=0.625$) and sickness absence related to epilepsy ($F=4.72$ $p=0.14$; pooled estimate variance $t=0.79$ $df=40$ $p=0.437$) are not significantly higher for the respondents with a seizure pattern which includes generalised seizures.

Table 9.20b Seizure pattern and total sickness absence (MR)

	N	Mean days	SD
Including generalised	37	63.35	73.89
Other	5	46.40	56.31
		NS	

Table 9.20c Seizure pattern and epilepsy-related
sickness absence (MR)

	N	Mean days	SD
Including generalised	37	38.05	64.77
Other	5	14.80	29.81
		NS	

Seven respondents said that they had seizures only during sleep. A statistical relationship was found between seizures occurring only during sleep and total sickness absence ($F=5.67$, $p=0.037$; separate estimate variance $t=2.10$ $df=21.31$ $p=0.047$). A relationship is also found for epilepsy-related absence ($F=13.86$, $p=0.003$; separate estimate variance $t=2.03$ $df=36.83$ $p=0.049$).

Table 9.20d Seizures occurring during sleep only
related to total sickness absence (MR)

<u>Seizures during sleep only</u>	N	Mean days	SD
Yes	7	31.14	31.92
No	38	67.45	76.02
		$p=0.047$	

Table 9.20e Seizures occurring during sleep only
and epilepsy-related sickness absence (MR)

<u>Seizures during sleep only</u>	N	Mean days	SD
Yes	7	11.71	17.38
No	38	36.87	64.69
		p=0.049	

One warning of poor work performance was issued to respondents who had seizures only during their sleep. Warnings were not related to seizures occurring during sleep (Fisher exact $p>0.386$). Restrictions were not related to this variables (Fisher exact $p>0.22$).

9.4.3.8 Incidence of seizures frequency

Respondents did not fall into a particular group in terms of seizure frequency. The frequency ranged from no seizures to more than one per week. There was no prominent pattern of seizure frequency for these respondents and seizure frequency would appear not to be an indicator of referral. All respondents with active epilepsy were in the group which had generalised seizures. Seizures were occurring significantly more frequently in the management referral sample than in the recruitment referral sample ($X^2=4.43$ $df=1$ $p<0.05$ $minEF=20.52$).

Table 9.21 Frequency of seizures (MR)

	(N=45)	
	Frequencies	%
More than 1 per week	8	18
<1 per wk > per mth	11	24
<1 per mth >1 per 6 mths	5	11
<1 per 6 mths >1 last yr	7	16
none in last year	14	31

As is illustrated in the table below, respondents with active seizures do not have a significantly different number of poor performance warnings issued than respondents without seizure occurrence (Fisher exact $p>0.27$). Nor do they had a significantly more restrictions placed on their employment (Fisher exact $p=0.22$).

Table 9.22a Seizure incidence and work performance

	n	Warning of Poor Perf.	Restrictions
Seizures	31	7 23%	14 45%
None last year	14	2 14%	5 35%
		NS	NS

For those respondents not having seizures, the amount of sick leave due to epilepsy is reduced ($F=10.80$ $p=0.000$; separate estimate variance $t=2.67$ $df=39.71$ $p=0.011$). However, the amount of total sickness absence does not show a significant difference ($F=1.20$ $p=0.754$; pooled estimate variance $t=0.27$ $df=43$ $p=0.788$).

Table 9.22b Seizure incidence and total
sickness absence (MR)

	N	Mean days	SD
Seizures	31	63.77	74.61
None last year	14	57.43	68.15
		NS	

Table 9.22c Seizure incidence and epilepsy-related
sickness absence (MR)

	N	Mean days	SD
Seizures	31	44.23	68.81
None last year	14	8.00	20.94
		p=0.011	

9.4.3.9 Increase in seizures

Fourteen respondents (31%) indicated an unstable seizure pattern. Five of these respondents had recently developed epilepsy. They had not been issued with more warnings of poor performance than the other nine respondents in this group (Fisher exact $p>0.3$), and had not received significantly more restrictions (Fisher exact $p>0.20$).

Table 9.23a Increasing seizure pattern and work performance (MR)

	n	Warning of Poor Perf.		Restrictions	
Increasing seizures	14	3	21%	7	50%
No increase	31	6	19%	12	39%
		NS		NS	

Sickness absence is shown to be high for this group, however a significant difference related to this variable cannot be found in total sickness absence ($F=2.98$ $p=0.013$; separate estimate variance $t=1.91$ $df=17.06$ $p=0.073$); nor in epilepsy-related sickness absence ($F=7.26$ $p=0.000$; separate estimate variance $t=1.74$ $df=14.64$ $p=0.103$).

Table 9.23b Seizure increase in the last 12
months and total sickness absence (MR)

	n	Mean days	SD
Increasing	14	97.14	93.70
No increase	31	45.84	54.23
		NS	

Table 9.23c Seizure increase in the last 12
months and epilepsy-related sickness absence (MR)

	n	Mean days	SD
Increasing	14	63.00	91.06
No increase	31	19.39	33.79
		NS	

A comparison with the recruitment sample could not be made on this variable (minEF=3.5).

9.4.3.10 Warnings of a seizure (aura)

Auras were experienced by 24 respondents (53%).

This was not significantly different to the proportion of respondents in the recruitment referral sample ($X^2=1.50$ df=1 $p>0.2$ minEF=17.49).

Of the respondents experiencing an aura, 13 respondents (29%) felt an aura preceding every seizure. Twenty respondents (44%) never felt an aura. If these two extremes of the range are compared (see 9.3.3.10) it is found that having an aura could not be demonstrated to be associated with either work performance (Fisher $p>0.32$), restrictions ($X^2=0.21$ df=1 $p=0.65$ minEF=5.12), or sickness absence (total sickness absence $F=1.28$

p=0.615, pooled estimate variance t=0.51 df=31
p=0.617; epilepsy absence F=1.23 p=0.73, pooled
estimate variance t=0.24 df=31 p=0.812).

Table 9.24	Auras of seizures	(MR)
	(N=44)	
	Frequencies	%
Always	13	30
Usually	4	9
Sometimes	7	16
Never	20	45

9.4.3.11 Recovery time

A range of recovery times were given from a few seconds to 24 hours. If the range is divided into two, using half an hour of lost time as the division, it is found that there were nineteen respondents (42%) taking less than half an hour to recover and twenty-four (53%) taking longer (two respondents were unable to answer this question). There was no difference in terms of sickness absence (total sickness absence F=1.44 p=0.43; pooled variance estimate t=0.67 df=41 p=0.51; epilepsy absence F=4.01 p=0.004; separate variance estimate t=1.51 df=35.29 p=0.139); nor poor work performance ratings (Fisher exact p>0.23) or restrictions ($X^2=0.927$ df=1 p=0.336 minEF=7.95). A significant difference was not found between the management and recruitment samples on this variable ($X^2=0.39$ df=1 p>0.5 minEF=20.8).

9.4.3.12 Co-incidental disorders

Fifteen respondents (33%) referred to co-incidental physical or mental disorders within the previous five years unrelated to epilepsy. The sickness absence of this group was high (mean of 89.2 days total and 22.5 days due to epilepsy), although no significant difference could be shown between this sub-group and the remaining members of the group (total sickness absence $F=1.15$ $p=0.724$; pooled estimate variance $t=1.86$ $df=43$ $p=0.07$; epilepsy absence $F=1.86$ $p=0.221$; pooled estimate variance $t=0.82$ $df=43$ $p=0.419$). There was also no difference in terms of warnings of poor work performance issued (Fisher exact $p>0.31$) or restrictions ($X^2=1.378$ $df=1$ $p=0.24$ $minEF=6.33$). A significant difference was not found between the management and recruitment samples on this variable ($X^2=2.57$ $df=1$ $p>0.1$ $minEF=10.96$).

On the questionnaire, thirty-two respondents (71%) said that their health was good or excellent. There was no difference between respondents reporting good or poor health in terms of sickness absence (total sickness absence $F=1.41$ $p=0.555$; pooled estimate variance $t=1.97$ $df=42$ $p=0.055$; epilepsy absence $F=1.59$ $p=0.42$; pooled estimate variance $t=0.35$ $df=42$ $p=0.726$). Two respondents

with poor health received warnings of poor work performance (Fisher exact $p > 0.31$) nor restrictions ($X^2 = 0.047$ $df = 1$ $p = 0.828$ $\text{minEF} = 5.182$).

9.4.3.13 Factors precipitating a seizure

Apart from stress there was no mention of precipitating factors found in the records. This issue was further examined in the questionnaire with both fixed and open response categories.

Table 9.25a Precipitating factors (MR)

	n	%	Warnings poor perf	Restrictions
<u>Fixed response</u>			p	p *
Alcohol	7	16	>0.30	>0.32
TV, flashing lights	11	24	>0.23	>0.26
Lack of sleep	14	31	>0.30	>0.12
Forgetting drugs	12	27	>0.27	>0.27
Stress at work	20	44	>0.29	>0.24
<u>Open response</u>				
Waking	1	2		
Excitement	1	2		
Periods	2	4		
Loud noise	1	2		
Dozing off	1	2		
Eating	1	2		

* Fisher exact test.

Table 9.25b Fixed response factors related to total sickness absence (MR)

	F=	p=	t=	df=	p=
Alcohol	2.71	0.21	1.54	43	0.13
TV, flashing	2.39	0.14	1.00	43	0.32
Lack of sleep	2.25	0.07	0.24	43	0.81
Forgetting drugs	2.43	0.12	1.97	43	0.07
Stress at work	1.98	0.12	0.95	43	0.35

Table 9.25c Fixed response factors and
epilepsy-related sickness absence(MR)

	F=	p=	t=	df=	p=
Alcohol	2.13	0.35	0.71	43	0.48
TV,flashing	2.28	0.17	0.77	43	0.45
Lack of sleep	2.72	0.02	0.43	17.46	0.67
Forgetting drugs	1.77	0.32	0.75	43	0.46
Stress at work	5.93	0.00	1.35	25.85	0.19

None of the factors thought to precipitate a seizure by the respondents were found to be associated with the dependent variables. The factor most often cited was stress at work.

9.4.3.13.1 Stress as a precipitating factor

The role of stress in the precipitation of seizures was examined through the records. Mention of stress was found in five cases (11%). These resulted in changes of work or grade. One record mentioned stress in relation to work-performance: in this case it was noted in the records that the stress had resulted in frequent and excessive use of alcohol which had caused complications with the medication. Stress at work as a precipitating factor for seizures was also examined through the questionnaire, here twenty respondents felt that stress was an important factor. These twenty respondents were not significantly different to the rest of the sample on ratings of poor work performance, restrictions or sickness absence. However, there were significantly more respondents

in the management referral sample who cited stress as a factor than there were in the recruitment sample ($X^2=4.08$ $df=1$ $p<0.05$ $minEF=14.46$).

9.4.3.14 Drug side effects

From the records it was found that questions about the side-effects of medication were raised by the medical advisors, who referred the issue to the employee's General Practitioner (GP). The Occupational Physician was reliant in each case upon the GP's understanding of epilepsy and their willingness to help. One confirmed case where medication had caused poor work-performance within the study period was found in this population. This was where lethargic behaviour had resulted in warnings of poor work-performance. Following several consultations with the employee's GP, it was decided to alter the medication. The employee's behaviour changed and she was able to provide a level of work-performance to the standard required of her. This case illustrates that adequate medical management is vitally important to the continued and successful work placement of people with epilepsy.

Thirty-two respondents (71%) reported that they were satisfied with their medication. The eleven respondents not satisfied with their medication

were not more likely to have received a warning for poor performance (Fisher exact $p>0.26$) or be more restricted in their work (Fisher exact $p=0.264$); nor were they more likely to take more sickness absence (total sickness absence - $F=1.1$ $p=0.788$; pooled estimate variance $t=0.99$ $df=41$ $p=0.33$) (epilepsy absence - $F=2.08$ $p=0.221$; pooled estimate variance $t=0.30$ $df=41$ $p=0.764$).

Respondents in the management referral study were significantly less likely to satisfied with their medication than respondents in the recruitment study ($X^2=12.63$ $df=1$ $p<0.001$ $minEF=5.95$).

9.4.3.15 Age of onset of epilepsy

The tables below show the distribution of age of onset of epilepsy. There were significantly more warnings issued to respondents with an age of onset less than 16 years (Fisher exact for this data-set or one more extreme $p=0.017$). There was no relationship with restrictions ($X^2=0.976$ $df=1$ $p=0.323$ $minEF=8.87$).

Table 9.26a Age of onset of epilepsy (MR)

	(N=45)	
	Frequencies	%
0 to 10 years	11	24
11 to 16 years	13	29
17 to 30 years	12	27
31 to 50 years	4	9
51 to 60 years	5	11

Table 9.26b Age of onset related to work performance and restrictions (MR)						
Age at onset	n	SD	Mean age now	Warnings Poor Perf.		Restrictions
0 - 16	24	9	33	8	33%	8 33%
17 - up	21	12	43	1	5%	11 52%
				p=0.017		NS

Age of onset is not correlated with either total sickness absence (Pearsons $r=0.097$) or epilepsy absence (Pearsons $r=0.111$). It can be seen that very little of the variance in the sickness absence figures is explained by the age of onset of epilepsy. The highest levels of sickness absence are found for people with recent onset of epilepsy. These five respondents are contained in the 17-30 age group.

Table 9.26c Age of onset - Sickness absence (MR)				
Age at onset	N	Mean days sick:-		
		Total	Epilepsy	
1 - 10	11	31.00	7.8	
11 - 16	13	59.46	22.23	
17 - 30	12	98.17	67.64	
31 up	9	46.13	26.75	
Mean	20.91	61.80	32.96	
SD	15.29	71.95	60.38	
Skewness	1.05	1.41	2.70	
Median	16yrs	29 days	1 day	
Correlation		r=0.097	r=0.111	

9.4.3.15.1 Recent onset of epilepsy

Five respondents (11%) had developed epilepsy within the previous two years. These respondents had not received any warnings of poor work-performance but were taking more total sickness absence ($F=2.89$ $p=0.69$; pooled estimate variance $t=2.75$ $df=43$ $p=0.009$) but did not indicate more epilepsy-related absence ($F=7.96$ $p=0.000$; separate estimate variance $t=2.47$ $df=4.13$ $p=0.067$).

Table 9.26d Recent onset and total sickness absence (MR)

	N	Mean days	SD
Recent	5	139.60	105.21
Non-recent	40	52.08	61.90
		$p=0.009$	

Table 9.26e Recent onset and epilepsy-related sickness absence (MR)

	N	Mean days	SD
Recent	5	137.40	105.49
Non-recent	40	19.90	37.39
		NS	

9.4.3.16 Onset after employment

Fifteen respondents had an onset of epilepsy after beginning work with the Civil Service. There was no difference between this group and the respondents with onset prior to joining the Civil Service; (warnings of poor performance - Fisher exact $p=0.099$; restrictions - Fisher exact $p=0.06$; total sickness absence - $F=1.56$ $p=0.30$, pooled estimate variance $t=0.57$ $df=43$ $p=0.571$; epilepsy absence - $F=2.83$ $p=0.02$, separate estimate variance $t=0.84$ $df=19.09$ $p=0.413$).

9.4.3.17 Behaviour at work

No respondents had received a warning for anti-social behaviour. However, it was noted that one non-respondent had received a warning for anti-social behaviour and at the time of the study was undergoing disciplinary action. It was noted by the Occupational Health Advisor that this employee was not having seizures at this time and had not had seizures at work.

9.4.3.18 Attitudes of managers and co-workers

Forty-one respondents (95%) indicated that their managers and co-workers were aware of their epilepsy. Only two respondents (5%) felt that managers were afraid of epilepsy, but six respondents (14%) said that their co-workers were

fearful of epilepsy. A statistical comparison with the recruitment sample cannot be made for management or co-worker attitudes (management attitudes minEF=1.17; co-worker attitudes minEF=2.8).

None of the respondents reporting fear in their managers or co-workers had been issued with warnings of poor performance. The group who thought that their managers were afraid of epilepsy did not have significantly more restrictions (Fisher exact $p=0.498$), nor were they taking more sickness absence (total sickness absence - $F=1.57$ $p=0.435$, pooled estimate variance $t=0.06$ $df=43$ $p=0.95$); (epilepsy-related absence - $F=301.81$ $p=0.091$, pooled estimate variance $t=0.73$ $df=43$ $p=0.472$). There was also no significant difference found for respondents identifying their co-workers as fearful (restrictions - Fisher exact $p=0.153$; total sickness absence - $F=1.19$ $p=0.945$, pooled estimate variance $t=0.62$ $df=43$ $p=0.541$; epilepsy-related absence - $F=1.31$ $p=0.832$, pooled estimate variance $t=0.39$ $df=43$ $p=0.701$).

9.4.3.19 Disrupted education

Respondents were asked if they felt that epilepsy had disrupted their education. Eighteen respondents (40%) felt that their education had been affected. This was not significantly different to the response given by the recruitment sample ($X^2=2.77$ $df=1$ $p>0.05$ $minEF=13.52$).

9.4.3.20 Social support problems

There were twenty-one respondents (47%) who reported a social support problem. Between them they registered 43 problems on the index. Eleven respondents (24%) recorded that they were having major problems in at least one area on the social support questionnaire. Four respondents reported two major problem areas and one respondent reported four areas causing a severe problem. The largest number of problems was found in the areas of 'work'; 'social activities' and 'domestic' arrangements. The number of respondents reporting social support problems was not significantly different between the management and recruitment referral samples ($X^2=1.95$ $df=1$ $p>0.10$ $minEF=17.02$) No comparison between the two samples on the number of respondents reporting 'marked problems' could be made ($minEF=3.96$).

No significant relationship between the group claiming to experience social support problems and sickness absence was found (total sickness absence $F=1.63$ $p=0.276$; pooled estimate variance $t=1.93$ $df=43$ $p=0.06$; epilepsy-related absence $F=3.48$ $p=0.007$; separate estimate variance $t=1.59$ $df=36.11$ $p=0.12$). Likewise there was no difference in terms of work performance (Fisher exact $p>0.29$), nor restrictions ($X^2=0.000$ $df=1$ $p=1.00$ $\min EF=8.87$).

Table 9.27 Social problem areas (MR)
(N=21)*

<u>Area</u>	<u>Frequency</u>
Housing	3
Occupation/social role	15
Finance	6
Social activities	9
Relatives	3
Marital/sexual role	2
Children	0
Domestic relationships	2
Legal matters	0
Living alone	2
Other	1

* Eleven respondents recording severe problems.

9.4.3.21 Seizures at work

Twenty-three respondents (51%) reported that at least one seizure had occurred at work. At least one generalised seizure had occurred at work for 20 of the respondents (44%). Significantly more respondents reported seizures at work in the management referral sample than in the recruitment sample ($X^2=27.11$ $df=1$ $p<0.001$ $minEF=5.36$).

There is no statistical difference in terms of work-performance, judged by warnings for poor-performance, between the respondents who had had seizures at work and respondents who had not (Fisher exact $p>0.17$). Likewise no relationship was found with restrictions ($X^2=0.000$ $df=1$ $p=1.00$ $minEF=9.29$).

Table 9.28a Seizures at work related to warnings of poor performance (MR)

Seizures at work	n	%	Warnings Poor Perf.	Restrictions
Yes	23	51	6 26%	10 43%
No	22	49	3 14%	9 41%
			NS	NS

A statistical difference cannot be shown for total sickness absence and seizures occurring at work ($F=2.36$ $p=0.054$; pooled estimate variance $t=0.70$ $df=43$ $p=0.488$), nor is there a relationship

between epilepsy-related sickness absence and seizures at work ($F=5.20$ $p=0.000$; separate estimate variance $t=1.50$ $df=30.45$ $p=0.144$).

Table 9.28b Seizures at work related to total sickness absence (MR)

	N	Mean days	SD
Yes	23	69.17	85.35
No	22	54.09	55.61
		NS	

Table 9.28c Seizures at work related to epilepsy-related sickness absence (MR)

	N	Mean days	SD
Yes	23	45.78	76.57
No	22	19.55	33.58
		NS	

9.4.3.20 Disruption due to seizures

There was no indication in the records of any disruption being caused by seizures occurring at work.

9.4.4 Main findings

The main findings from the management referral study are as follows:

- # 69% of the sample had active epilepsy.
- # 88% of the sample had a seizures which were generalised.

- # The mean total sickness absence for this sample was 62 days with 33 days attributed to epilepsy.
- # The greatest total sickness absence was recorded for those respondents having recent onset.
- # 51% of the sample had had seizures at work but work performance and sickness absence were not related to the occurrence of seizures at work.
- # Poor work performance was significantly related to lower age of onset of epilepsy.
- # 42% of the sample had some form of restriction placed on them by management. The restricted group could not be distinguished from the other respondents on the basis of the independent variables measured here.
- # 47% of the respondents imposed restrictions upon themselves. 22% of the sample imposed their own restrictions were these were not imposed by Occupational Health.
- # There was significantly less sickness absence related to epilepsy if the respondents did not have active epilepsy or the seizures occurred only during sleep.

9.5 Summary of Civil Service studies

In this chapter I have examined two samples of employees with epilepsy. These samples came from different populations in the Civil Service. They were distinguished initially by the method of referral to the study. On examination they are also distinguished by the following characteristics:

- 1) epilepsy factors - greater likelihood of seizure occurrence, more likely to have generalised seizures, greater dissatisfaction with medication;
- 2) occupational factors - having greater amounts of sickness absence, more likely to cite stress as a precipitating variable and more likely for seizures to occur at work.

They were not distinguished by the imposition of self-restrictions, the occurrence of auras, their recovery time following a seizure, believing that their education had been disrupted by their epilepsy nor by the presence of a physical or mental illness or disability in the previous five years.

In the recruitment respondents the mean age of respondents was 27 years. Recruitment was to clerical and manual staff of Executive Officer grade and below. The sample can be shown to be

composed of a group of people of whom 93% are performing to within the work performance criteria of their line managers. Sickness absence is low and only one day on average is recorded for the sickness absence due to epilepsy.

If we now turn to the management respondents, we see a set of characteristics emerging which describe a group of employees which are seen as having a 'problem'. They are drawn from an older age group, (mean age 37 years), however there were no referrals above Executive Officer grade. Eighty two percent of the sample experienced generalised seizures; 69% had seizures in the last twelve months; 31% had increasing seizure frequency; and 11% had recent onset of epilepsy. Almost half the sample (47%) had onset of epilepsy after age 16 years. There was a total sickness absence mean of 62 days and absence related to epilepsy was a mean of 33 days. Poor work performance was recorded in nine respondents (20%). A relationship was noted between poor work performance and early age of onset of epilepsy. It can be seen that the early onset group were also younger at the time of the survey (mean age 33 years compared to 43 years for onset after 16 years) which could contribute to this finding.

Relationships found within the data suggest that the problem of high sickness absence is related to two factors. It was found that in the recruitment and management referral studies that active seizures related to higher levels of epilepsy-related sickness absence and it was found in the management study that recent onset related to higher total sickness absence.

Qualitative evidence drawn from the records suggests that another possible problem area is employment restrictions. Employment restrictions were placed on 42% of the management respondents; however, the exact interpretation of the restriction was vague. It is surprising that restrictions are not found to be related to aspects of the medical condition, one possible explanation for this is that there may be a delay between noticing a problem and the imposition of restrictions. It could take some time before restrictions are put into place. The self-restrictions imposed by twenty-one respondents (47%) may have been more limiting than those imposed by the employer, which suggests that some of the respondents could be denying themselves opportunities unnecessarily.

It is of note that a very high proportion of respondents do not view their managers and co-workers as fearful of epilepsy. This contradicts the literature.

9.6 Areas requiring further analysis

The above analysis points towards the need to know more about several areas concerning the individual with epilepsy in the work-place. In particular, we need to know more about: the effects of age of onset on career; the problems in education and training; the effects of seizures at work; and more information on the attitudes of managers and co-workers to the employee with epilepsy. These areas will be explored in greater depth in the following study. The Civil Service studies have also found most respondents within the clerical area of work, but this may reflect the nature of the profession rather than an outcome of epilepsy. The next study will look at a profession with a different composition of types of employment.

CHAPTER TEN

THE NHS STUDY

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10.1 Background to the survey

In 1986 the Association for National Health Service Occupational Health Physicians identified the need for better guidance regarding the employment of people with epilepsy in the NHS. They recognised that this could only come from a fuller understanding of the issues involved and so the Association commissioned research into this area.

In order to determine prevalence of epilepsy in the NHS population a separate questionnaire was sent, with the initial contact letter, to all 56 health districts in the four London Thames regions requesting a prevalence figure for employees with active epilepsy i.e. a narrow definition (see section 2.6) and if a policy towards the

employment of people with epilepsy was in force. The survey was conducted between May and July 1987: replies were received from 44 districts. Although figures were returned for the size of the NHS employed population with epilepsy it was noted that in only one case did a 'register of known epileptic employees' exist, all other figures were based on the Occupational Health Staff's knowledge of the workforce.

Eight districts were unable to give a figure and one district said that there was no one with epilepsy employed. The table below presents the frequency of different prevalence figures found in those districts returning figures.

Table 10.1 Crude prevalence rate in the NHS

Prevalence (per 1000)	Districts N = 36
None	1
< 0.5	4
0.5-0.9	11
1.0-1.4	8
1.5-1.9	3
> 2.0	9

The mean prevalence figure was 1.99 per 1000 NHS employees and a standard deviation of 2.1. These figures are in line with those previously found from a random sample of 48 districts, surveyed in

1985 using the same methodological approach (Lisle & Waldron, 1986). Lisle and Waldron (1986) found that the prevalence of employees with epilepsy in the NHS was between 0.2 and 5.0 per 1000.

Twenty two districts provided information on policies adopted towards the employment of people with disabilities. None of the districts replying had a specific policy on epilepsy. An indicator of NHS policy towards people with epilepsy may be taken from the type of job barred by each district's selection procedure.

Thirty three districts indicated that they barred certain jobs to people with epilepsy. The qualification for exclusion varied. For example, five districts said there was no specific bar but certain jobs would be unsuitable. A further three districts said that there was no agreement between hospitals within their district on what jobs should be barred. The remaining districts said there was a bar, without qualification, on certain types of job. The jobs most commonly mentioned were driving, work that involved dangerous or moving machinery and work that involved being at heights, up ladders and so on, including painters and electricians.

Nursing posts or certain nursing duties were barred by eleven districts. Two districts said that all nursing posts would be barred. However, the others nine districts either mentioned certain areas, such as working in theatre and midwifery, as being barred or specified duties such as working alone, working at night, giving injections and handling infants.

This chapter deals with a survey of work experiences of NHS employees with epilepsy in the four Thames health regions.

The study was questionnaire-based. The questionnaire used was an adapted version of the one sent to people with epilepsy in the Civil Service in the previous study. The questionnaire was sent to potential respondents via the Occupational Physician, this procedure being adopted in order to preserve anonymity of the respondents. The main study was conducted over a period of one year from July 1987 to June 1988. The issues of particular importance to this study were effects of age of onset on career, problems in education and training, the circumstances around seizures at work, and attitudes of managers and co-workers at work.

There are 56 districts in the four Thames regional health authorities. Each district was asked to help in identifying potential respondents and to administer the questionnaire. The initial contact letter to Occupational Physicians was addressed from the NHS Occupational Health Working group and asked for their help in completing the research.

Forty-four Health Districts answered the initial questionnaire and of these thirty-six could identify employees with epilepsy. Occupational Health Staff (OHS) were asked to forward questionnaires to all employees with epilepsy.

10.3.1. Data collection

Data were obtained from a self-completion questionnaire. This was a revised version of the Civil Service questionnaire (see Appendix 1). It was composed mainly of multiple choice questions. Each questionnaire was assigned a reference number to be the only distinguishing mark on the questionnaire.

Independent measures of work performance and sickness absence were not made available for study.

10.3.2. Procedure

Occupational Physicians were asked to address and forward pre-numbered questionnaires. They recorded to whom these questionnaires were sent and the accompanying reference number. This record was the only method of identifying the respondent. Once the questionnaires had been forwarded, the Occupational Physician was then asked to return a slip stating how many questionnaires had been forwarded.

10.3.3 Response rate

There were 114 employees referred by Occupational Health staff. Eighty-three respondents returned questionnaires, which is a response rate of 73%.

10.3.4 Reasons for non-return of questionnaires

From the limited data available on the 31 employees who did not return the questionnaire it was found that in four cases the Occupational Health Physician judged that their literacy standards were below that required for the questionnaire; four subjects left the NHS during the period of the study. The remaining twenty-three cases were followed-up by the Occupational Health Staff, non-respondents reported that they were "too busy" (n=3); felt the questionnaire was "too difficult" (n=6); "not confidential enough" (n=8); or gave no reasons for non-return (n=6). Occupational Health Staff reported that these subjects did not characteristically differ from respondents on demographic or medical grounds. Information obtained on non-respondents included age, sex and type of job. Comparisons between the sample and the total population were conducted using Kolmogorov-Smirnov one-sample test and the chi-square goodness-of-fit test. An alpha of 0.10 was chosen in order to have greater confidence that no difference exists when not rejecting the null hypothesis of no difference (i.e. the avoidance of a type 2 error). From the tables

below it is seen that respondents can be considered as representative of the total referral population.

Table 10.2a		Age		
Age	(n=114)		(n=83)	
	Referrals		Respondents	
		%		%
16 - 20	16	14	9	11
21 - 25	17	15	14	17
26 - 30	14	12	14	17
31 - 35	9	8	8	10
36 - 40	19	17	14	17
41 - 45	14	12	9	11
46 - 50	7	6	6	7
50 +	15	13	9	11
Mean age	37 years		34 years	
Standard deviation	19		18	
K-S	D=0.044			
	critical value at $\alpha=0.1$ $\frac{1.22}{\sqrt{83}} = 0.13$ NS			

Table 10.2b		Sex		
	(n=114)		(n=83)	
	Referrals		Respondents	
		%		%
Males	42	37	31	37
Females	72	63	52	63
minEF=37	df=1	X ² =0.0	p<0.1	NS

Table 10.2c		Type of job			
		(n=109)		(n=80)	
		Referrals		Respondents	
		%		%	
Nursing		48	44	40	50
Manual work		39	36	26	33
Clerical		12	11	9	11
Other		7	6	5	6
minEF=5	df=3	X ² =1.024		p>0.7	NS

10.4 Demographic characteristics of respondents

Thirty-one respondents were male and fifty-two respondents were female. Forty-one of the respondents were married, out of whom fifteen were male and twenty-seven were female. Seven respondents were divorced or separated.

Thirty-eight per cent of the women and forty-five per cent of the men were single.

The average age of male respondents was 35 years (SD=17) and of female respondents 33 years (SD=20). A breakdown of the overall age range is shown in table 10.2a.

Twelve respondents (14%) were registered as disabled (eight male and four female). People registered as disabled were found mostly in manual work and none in high status occupations.

Table 10.3a Registration of disability (N=80)*

	n	Registered	
Nursing	25	3	12%
Manual Work	23	8	35%
Clerical Work	9	1	11%
Senior Nurse	15	0	0%
Senior Manual Work	3	0	0%
Doctor	2	0	0%
Engineer	1	0	0%
Management	2	0	0%

* Three respondents withheld this information

The respondents were drawn from the four Thames regions. The distribution is shown in the table below.

Table 10.3b Location of respondents

	Frequency (N = 83)
North East Thames	13
North West Thames	27
South East Thames	28
South West Thames	15

10.4.1 Education

Respondents were asked to indicate their highest level of education achieved. The qualifications described were grouped under five headings of equivalent status. Almost a third of the group (twenty-four respondents) had not obtained any qualifications, and another third had gained A' Level/ SRN or above qualifications.

Table 10.3c Education

	Frequency
No qualifications	24
CSE	7
'O' level/SEN	24
'A' level/SRN	24
Degree/Further Education Certificate	4

10.5 _____ Employment problems

10.5.1 Epilepsy affecting present job

Four respondents said that epilepsy adversely affected their present work. Two of these respondents were in senior posts and two in clerical.

10.5.2 Epilepsy affecting career

Twenty-three per cent of the sample felt that their careers had been affected by having epilepsy. The highest level of perceived problems were felt in senior nurses. This was a significantly higher figure than that found in non-senior nursing grades (Binomial test $p=0.043$). There was no difference between manual and senior manual grades ($p=0.53$).

Table 10.4 Career affect by type of work (N=80)*

	n	Career affected	%
Nursing	25	5	20
Manual	23	4	17
Clerical	9	2	22
Snr Nurse	15	6	40
Snr Manual	3	1	33
Doctor	2	0	0
Management	2	0	0
Engineer	1	0	0
		<u>18</u>	

* three respondents did not give their job titles.

10.5.3 Career difficulties related to age of onset

If the reporting of career difficulties is related to age of onset of epilepsy, it is found that with later onset, more respondents say that epilepsy has affected their careers.

Table 10.5 Career difficulties - age of onset

Age of onset	N	Frequency	%
1 - 5	8	2	25
6 - 10	10	1	10
11 - 15	19	2	11
16 - 20	14	7	50
21 - 30	19	4	21
31 - 40	10	2	20
41 upwards	3	0	0
		18	

If age of onset does not affect career difficulties there should be no difference between the age groups on this variable. When a distribution of no difference was compared to the observed distribution, a significant difference was observed (Kolmogorov-Smirnov one-sample test: critical value ($\alpha=0.05$) =0.152; D=0.16). Half of the respondents with a first seizure between ages 16 and 20 years thought that epilepsy would affect their career. This coincides with the period when most nurses join the profession and make career choices.

10.5.5 Problems during training and education

Twenty-one respondents (25%) said that they had had a problem at some time during their training. Only ten respondents made a further comment on this question. Five of these comments were from nurses. The teaching and training establishments were criticised for being unsure of how to treat someone with epilepsy. In several cases, training could only be completed after much discussion and long periods of uncertainty.

One nurse complained of the "ridiculously short periods of sick leave" allowed to student nurses, which makes it quite impossible to gain control of the epilepsy and meet the attendance requirements of the course. A doctor who also started to have seizures during training said that he had to review his choice of medical specialism. As epilepsy may be difficult or dangerous in certain areas, advice on future prospects were considered very important at this time.

10.5.6 Employment advice

There were twenty-three respondents (28%) who had had advice on employment. Three respondents had been given information from more than one agency. These agencies are shown in the table below. Advice from the Occupational Health Service had been given to two respondents who had had their first seizure after starting work with the NHS. One nurse complained that the "very thorough " medical she was given had made her feel "very insecure". She said that great emphasis was laid on "- keeping an eye on me" but following the medical no one from Occupational Health had made any contact with her.

The table is also divided into respondents who had onset of epilepsy before and after starting work with the NHS. It should be noted that most respondents (72%) had not received any advice.

Table 10.6 Frequency of advice received

	(N=70) Pre NHS onset	(N=13) Post NHS onset
Voluntary Organizations	9	0
Occupational Health Department	8	2
Job Centre	4	0
Teaching Establishments	3	0

The respondents were asked what form the advice took. In all cases the advice was that particular jobs should not be undertaken. Fourteen nursing respondents reported that they were advised against nursing. The type of nursing they were advised against was:-

"Midwifery"

"Community nursing, due to needing to drive."

"Nursing or hospital work."

"District nursing."

"Charge nurse post."

The other jobs which people were advised against included "police work" and "working with a VDU".

Respondents were also asked if they got the job they originally wanted and 42 respondents said that they did. If we look at this in relation to pre- and post-employment diagnosis we find that three quarters of the group having a diagnosis after joining the NHS said that the job they got in the NHS was their first choice (ten out of thirteen), but in the pre-employment diagnosis group only just under half (N=32) said that the job they got in the NHS was their first choice (see table 10.7). This is a significant difference between the groups (chi sq=5.62 Min EF=6 $p<0.02$).

Respondents were more likely to get the job of their first choice if they didn't have epilepsy at the beginning of their careers.

	Job choice	
	Pre-employment diagnosis	Post-employment diagnosis
First choice of work	32	10
Not first choice	<u>38</u>	<u>3</u>
	70	13
	p<0.02	

10.6 Testing the biopsychosocial framework

The following sub-sections are divided into the elements of the biopsychosocial framework (see table 7.1). It has only been possible to collect categorical or ordinal data in this study and therefore statistical analysis will be made with non-parametric tests.

Where possible the exact probabilities will be calculated using a Fisher exact test. If the observed distribution is non-significant, more extreme frequencies will not be calculated and the significance level will be presented in the form of greater than ($p>$). However where there are no more extreme frequencies or where the frequencies show a significant difference the exact significance value will be shown ($p=$). A Kolmogorov-Smirnov two-sample test is used to examine the relationship between age of onset and seniority of nursing and manual grades; as the sample size is above 25, the critical value of alpha ($p=0.05$) is calculated by -

$$1.36\sqrt{\frac{m+n}{mn}}$$

where m is the size of the first sample and n is the size of the second (p147. Siegel & Castellan, 1988).

Dependent variables

10.6.1 Type of job

The type of work performed by the respondents was roughly divided into categories of work, shown in the table below. The majority of respondents are nurses, with the second highest group being manual workers.

The grade of job will be used as the dependent variable in subsequent analyses. For convenience of statistical comparison this variable can be divided into high and low status jobs. Although this division is clear for most job titles there is ambiguity as to the status of the job title 'engineer', therefore this respondent is dropped from comparison of high and low status.

Comparisons are also possible between senior and non-senior nursing and manual grades.

Table 10.8	Type of work
	(N=80)*
<u>Low status</u>	n
Nursing	25
Manual Work	23
Clerical Work	9
<u>High status</u>	
Senior Nurse	15
Senior Manual Work	3
Doctor	2
Management	2
Engineer	1

* Three respondents withheld this information

10.6.2 Work performance

No objective measure was available in this study.

10.6.3 Sickness Absence

From the responses on the questionnaire it was found that sixty-two respondents took sickness absence over the previous twelve months. This represents 75% of the total sample. Of these, twenty-three respondents (28%) took absence related to epilepsy. The modal category of lost time due to sickness for the whole group was 'one to two weeks'. The modal category of time lost due to epilepsy was much smaller, being 'less than a week'. No objective data were available on this measure, therefore further analysis of this measure was not undertaken.

10.6.4 Shift work

Clerical and management respondents were not working shifts but all other respondents were on shift work.

10.6.5 Restrictions on employment

Documentary evidence was not available on this variable.

10.6.6 Accidents at work

Three respondents reported that they had received an injury during a seizure at work sometime in the past. None of the respondents said that a seizure had resulted in an injury to another person. From the group of twenty-one respondents who had had a seizure at work within the last 24 months, eight respondents (10% of the total group and 38% of these respondents having seizures at work) reported that medical attention had been called and three respondents said that as a result of this they had to attend a subsequent medical examination. (see also section 10.6.21/2)

Independent variables

10.6.7 Type of seizure

Respondents were asked to describe their main type of seizure and these were subsequently classified as either a pattern which included generalised seizures, or other seizure patterns. Table 10.9a below describes the proportion of these.

As shown in table 10.9b, a relationship was found between type of seizure and job status ($X^2=5.08$ $df=1$ $p<0.05$). However there was no relationship found between seizure type and seniority of nursing (Fisher exact $p>0.17$) or seniority of manual posts (Fisher exact $p>0.15$).

Table 10.9a Type of work compared to seizure type

	N=83 n	N=46 Inc gen.	N=41 Other
Nursing	25	12	13
Manual work	23	18	5
Clerical work	9	6	3
Senior Nurse	15	5	10
Senior Manual work	3	1	2
Doctor	2	1	1
Management	2	0	2
Engineer	1	0	1
Job not given	3	3	0

Table 10.9b Job status and seniority compared
to seizure type

Seizure type	Status		Manual		Nurse	
	Low	High	non-Snr	Snr	non-Snr	Snr
Including generalised	36	7	6	0	9	0
Other	21	16	17	3	16	15
	p=<0.05		NS		NS	

10.6.8 Seizures frequency

Thirty-seven respondents (45%) said that they were seizure-free and had not had a seizure in the last two years. Two of these respondents said that they had a variable seizure pattern which meant that they were unsure if they would remain seizure-free. The remaining respondents (55%) had had seizures in the last six months and in two cases seizures were occurring on a weekly basis. The seizure-free group had had on average less than ten seizures in their lifetime: eleven respondents (13%) had had less than three seizures in total.

Those respondents with active epilepsy were not found more frequently in low status jobs as opposed to high status jobs ($X^2=3.06$ $p>0.05$ $\text{minEF}=10.03$). Comparisons between senior nurse and nurse grades (Fisher exact $p>0.15$) and senior manual and manual grades (Fisher exact $p>0.32$) were also non-significant.

Table 10.10a Job type related to occurrence of seizures

	Active epilepsy		Seizure-free	
Nursing	16	(70%)	9	
Manual	14	(67%)	9	
Clerical	5	(56%)	4	
Senior nursing	7		8	(53%)
Senior manual	1		2	(67%)
Doctor	0		2	(100%)
Management	0		2	(100%)
Engineer	0		1	(100%)
Job not given	3	(100%)	0	
	46		37	

Table 10.10b Status and seniority compared to occurrence of seizures

Seizures in last 2 yrs	Status		Manual		Nurse	
	Low	High	non-Snr	Snr	non-Snr	Snr
Active	35	8	14	1	16	7
Seizure-free	22	14	9	2	9	8
	NS		NS		NS	

10.6.9 Increasing frequency

There was no indication in this group of respondents having increasing seizure frequency within the previous two years.

10.6.10 Warnings of a seizure (aura)

The majority of respondents received a warning prior to a seizure. Warnings preceded all seizures for 31% of the sample and a further 24% had warnings at least some of the time. There was no relationship between having a warning and type of job status ($X^2=1.04$ $df=1$ $p>0.30$ $minEF=6.77$) nursing posts (Fisher exact $p>0.22$) or manual posts (Fisher exact $p>0.45$).

Table 10.11a Auras (Warnings of a seizure)

Warnings of a seizure	Frequency	%
Always	26	31
Usually	6	7
Sometimes	14	17
Never	33	40
Don't Know	4	5

Table 10.11b Status and seniority compared to auras

Auras	Status		Manual		Nurse	
	Low	High	non-Snr	Snr	non-Snr	Snr
Always	17	8	8	1	9	5
Never	26	8	15	2	16	10
	NS		NS		NS	

Of those respondents receiving an aura (55%) the majority had less than 15 minutes warning of a seizure and many only had a few seconds warning.

10.6.11 Recovery time following a seizure

The recovery time following a seizure varied from a few seconds to more than a day. The table below shows how much time respondents needed to recover from their seizures. Forty six per cent of the respondents claim to recover from a seizure in half an hour or less. Given that 20% of the sample were unable to give a precise response, this data is not taken as representative of the group as a whole and is therefore not compared to the dependent measure.

Table 10.12 Recovery time following a seizure

	Frequency	%
Up to half hour	38	46
An hour	8	9
Up to 6 hours	12	14
Up to 12 hours	3	4
A day or more	6	7
Varies	16	20

10.6.12 Co-incidental disorder

Respondents judged their general health on a four-point scale ranging from excellent to poor. Only nine people viewed their health as below good.

Table 10.13a	General Health	
	Frequency	%
Excellent	22	26
Good	52	63
Fair	6	7
Poor	3	4

Thirteen respondents (15%) said that they had a disability in addition to epilepsy, as shown in the table below. Respondents with co-incidental disorders were all found in non-senior posts, eight respondents in nursing grades and five in manual grades.

Table 10.13b Co-incident disorders

Multiple Sclerosis	2
Diabetes	1
Asthma	3
Arthritis	4
Systolic heart murmur	1
Partial Deafness	1
Cerebral palsy	1

Table 10.13c Co-incident disorders compared
with seniority of nursing and manual posts

Co-incident disorder	Status		Manual		Nurse	
	Low	High	non-Snr	Snr	non-Snr	Snr
Yes	13	0	5	0	8	0
No	44	22	17	3	16	15
	minEF=3.62		NS		p=0.007	

It was found that the presence of co-incident disorders was related to seniority in nurses (Fisher exact $p=0.007$); however, the relationship was not found for manual workers (Fisher exact $p=0.44$). A comparison on job status could not be made as one expected frequency was below five (minEF=3.62).

10.6.13 Factors precipitating a seizure

Respondents were asked to indicate possible precipitating factors to which they attributed their seizures. Thirty respondents (36%) said that they could not attribute their seizures to anything. The factor which is most often cited as

a cause of a seizure is 'lack of sleep'. The second most frequently cited factor is stress at work.

Table 10.14a Number of Precipitating factors
(N=53)

	Frequency	%
Lack of sleep	21	40
Stress - work	16	30
VDUs & flashing lights	15	28
Anger	8	15
Alcohol	6	11

Categories supplied in the questionnaire.

10.6.13.1 Stress

One in five respondents (16/83) saw stress at work as a possible factor in producing seizures. No relationship was found between the reporting of stress at work precipitating seizures and seniority of nurses (Fisher exact $p > 0.29$) or of manual posts (Fisher exact $p = 0.68$). A comparison with high and low status jobs could not be made using chi square due to one expected frequency below five (minEF=4.46).

Table 10.14b Seizures caused by work stress

Stress-induced seizures	Status		Manual		Nurse	
	Low	High	non-Snr	Snr	non-Snr	Snr
Yes	11	5	3	0	6	3
No	46	17	20	3	19	12
	minEF=4.46		NS		NS	

10.6.14 Drug side effects

Seventy-two respondents said that they took medication for epilepsy. Forty-eight respondents took only one drug, twenty respondents took two drugs and four respondents took three or more. Seventeen respondents (20%) said they were taking medication other than anticonvulsants. The anti-epileptic medication taken is shown below.

Table 10.15 Anticonvulsants used

	Frequency
Phenytoin	34
Sodium Valproate	22
Carbamazepine	19
Phenobarbitone	11
Primidone	7
Ethosuximide	4
Clonazepam	2
Clobazam	1
Sulthiame	1
Nitrazepam	1

Eighty-three percent of the population were satisfied with their medication. However, 37% of respondents mentioned side-effects from either the drugs they were taking at the moment or drugs they had taken in the past. The drugs which had the greatest number of problems were Phenytoin and (to a lesser extent) Carbamazepine. Respondents were uncertain when side effects had occurred and therefore, this variable is not compared with the dependent variable of seniority.

10.6.15 Age of onset of epilepsy

The mean age of first seizure was 19 years with a standard deviation of 10 years and the mean age of diagnosis was 20 years with a standard deviation of 10 years. The distribution of ages was similar to a normal distribution. This would not be predicted from the literature (see 2.4.5.).

Table 10.16a Age of onset of epilepsy (N=83)

Age of onset	Frequency	%
1 - 10	18	21
11 - 20	33	40
21 - 30	19	23
31 - 40	10	12
41 upwards	3	4
Mean	19 years	
Standard deviation	10 years	
Median	16 years	

10.6.15.1 Seniority related to age of onset

In the tables below the age of onset of epilepsy is related to the type of work (manual and nursing) and the level of work performed (senior or non-senior). The largest onset category for nurses was 21 and 30 years which is the period after training / career choice has been established.

Table 10.16b Seniority and onset (Manual grades)

Age of onset	N	(n=3) Senior posts	(n=23) Non-senior posts
1 - 5	3	0	3
6 - 10	3	0	3
11 - 15	4	0	4
16 - 20	2	1	1
21 - 30	6	2	4
31 - 40	5	0	5
41 upwards	3	0	3

Critical value ($\alpha=0.05$) =0.61 D=0.455 NS

Table 10.16c Seniority and onset (Nursing grades)

Age of onset	N	(n=15) Senior posts	(n=25) Non-senior posts
1 - 5	3	1	2
6 - 10	4	2	2
11 - 15	9	2	7
16 - 20	9	1	8
21 - 30	12	6	6
31 - 40	3	3	0
41 upwards	0	0	0

Critical value ($\alpha=0.05$) =0.326 D=0.255 NS

A Kolmogorov-Smirnov two-sample test was used to determine if differences existed between senior and non-senior positions in relation to age of onset of epilepsy. There was no significant difference between senior and non-senior posts for manual grades (D=0.455 $p>0.05$) or for nursing grades (D=0.255 $p>0.05$).

10.6.16 Onset after employment

Thirteen respondents (16%) had been diagnosed as having epilepsy after starting work for the NHS. Their mean age at the time of the survey was thirty-six years and the mean age of their onset of epilepsy was twenty-nine years with a range of between eighteen to forty-four years.

A question generated by the literature review has been what effect a diagnosis of epilepsy has on the individual's career. It is possible to seek evidence related to this in the NHS, by examining the differences between employees with a diagnosis before and after recruitment. The sample was therefore divided into two groups. Those respondents with a diagnosis of epilepsy prior to starting work with the NHS (seventy respondents) and those who were diagnosed as having epilepsy after they joined the NHS (thirteen respondents).

Table 10.17a Division by time of diagnosis

Diagnosis prior to joining the NHS n = 70	Diagnosis after joining the NHS n = 13
Mean age = 34	Mean age = 35.6
Mean age onset = 17	Mean age onset = 29

If these two groups are compared in terms of job status, it can be demonstrated that the number of people diagnosed after joining the NHS is distributed by chance between low and high status jobs (Binomial test $p=0.29$). However, the chance of being in a low status job if onset of epilepsy is prior to joining the NHS is above chance (Binomial test $p=0.000$). Respondents with a diagnosis prior to joining the NHS could be found significantly more often in low status jobs. As you can see from the table below, the latter group are more often found in the high status jobs. The relationship is not shown for senior manual and senior nursing posts (Nurses - Fisher exact $p>0.23$; Manual work - Fisher exact $p>0.36$).

Table 10.17b Type of job by time of diagnosis

		Diagnosis prior to NHS		Diagnosis after joining NHS	
	n		%		%
<u>Low status</u>					
Nursing	25	21	31	4	16
Manual	23	20	30	3	13
Clerical	9	9	13	0	0
<u>High status</u>					
Senior Nursing	15	11	16	4	27
Senior Manual	3	2	3	1	33
Doctor	2	2	3	0	0
Management	2	2	3	0	0
Engineer	1	0	0	1	100
		67		13	

Table 10.17c Seniority compared to time of diagnosis

<u>Diagnosis</u>	<u>Status</u>		<u>Manual</u>		<u>Nurse</u>	
	<u>Low</u>	<u>High</u>	<u>non-Snr</u>	<u>Snr</u>	<u>non-Snr</u>	<u>Snr</u>
Prior to NHS	50	17	20	2	21	11
	p=0.000*					
Post NHS	7	5	3	1	4	4
	NS*		NS		NS	

* Binomial test

10.6.17 Behaviour at work

There was no objective measure of this variable available.

10.6.18 Attitudes of managers and co-workers

10.6.18.1 Line manager's attitudes

Eighty-one respondents (98%) said that their line managers were aware of their epilepsy. Of the two respondents who thought their managers were not aware, one worked as a nurse and the other in a clerical job.

Respondents also asked if their manager's attitudes were negative or positive towards epilepsy, using a five point Likert-type scale where '1' indicated negative feelings and '5' indicated positive feelings. The overall result showed a tendency towards a positive attitude, with a median of '4'. The figures are given below.

Table 10.18a Line manager's attitude

	Frequency	%
Negative 1	13	16
2	5	6
3	12	14
4	5	6
Positive 5	41	49
Not answered	7	9

The majority of respondents felt that their managers have a positive attitude to their epilepsy. There are, however, thirteen respondents who hold the opposite opinion, none of whom were found in high status jobs. If these two groups are compared (high and low status jobs) assuming that the occurrence of negative attitudes would be randomly distributed across job type, which would be the case if job type is not affecting these attitudes. Negative attitudes, therefore ought to be found in one in eight respondents in each job group. It is found that the distribution of negative attitudes observed is significantly different from a random distribution (Binomial test corrected for continuity $p < 0.000$). Therefore attitudes are related to job type.

10.6.18.2 Co-workers' attitudes and awareness

Sixty-six respondents (80%) said that their fellow workers knew of their epilepsy. There were sixteen respondents who said that their fellow workers did not know of the epilepsy. This group is broken down by occupation category in the table below.

Table 10.18b Co-workers did not know of epilepsy

	N	Frequency	%
Manual	23	5	19
Nursing	25	8	20
Doctor	1	1	50
Engineer	1	1	100
Job title not given	3	1	33

Respondents reported that their co-workers' attitudes were mainly positive. See table below.

Table 10.18c Co-workers' attitude

		Frequency	%
Negative	1	12	14
	2	2	3
	3	7	8
	4	10	12
Positive	5	35	42
Not answered		17	20

The most frequent response is 'positive'. The twelve respondents who felt that their co-workers were negative were the same as those who found their manager's attitude negative. Only one

respondent felt there was a very negative attitude from co-workers and a very positive attitude from the manager. Negative attitudes broken down by work areas are shown in the following table.

Table 10.18d Negative attitudes by type of work

	N	Frequency	%
Manual	23	4	14
Nursing	25	3	8
Clerical	9	3	33
Job title not given	3	2	66

The same pattern of responses is found to that of managers attitudes in that there are no responses from high status jobs (Binomial corrected for continuity $p < 0.000$).

10.6.19 Disrupted education

Respondents were asked to state whether they felt that epilepsy had affected their education. Twenty respondents (24%) claimed that epilepsy had been a problem during education, either at school or afterwards.

10.6.20 Social support

Marked problems with social support were recorded by five respondents (6%). Four of these respondents recorded problems in more than one area. One respondent recorded problems in seven areas. The areas receiving the highest frequency of responses were those of:- finance (4 respondents); interaction with relatives (3 respondents); and satisfaction with job/interaction with work colleagues (2 respondents). All respondents with social support problems were in low status jobs.

10.6.21 Seizures at work

Twenty-one respondents (25%) had had seizures at work during the last two years. In the majority of cases, respondents had only had one seizure during this period, of which 29% were generalised. However, in two cases there were more than twenty seizures; both of these respondents had partial seizures only and were in manual employment.

Table 10.18a Number of seizures at work in the last two years

Number of seizures	Frequency
One	12
Two	5
Three	0
Four	1
Five to ten	0
Eleven to twenty	1
Over twenty	2
	21

Table 10.18b Seizures at work related to job type

	N	Freq.	%	Gen- ralised
Nursing	25	8	35	1
Manual	23	7	28	1
Clerical	9	3	33	2
Senior Nursing	15	1	7	0
Senior Manual	3	0	0	0
Management	2	0	0	0
Doctor	2	0	0	0
Engineer	1	0	0	0
Job title not given	3	2	66	0

Table 10.18c Seizures at work compared to seniority of nurses and manual grades

Seizures at work	Status		Manual		Nurse	
	Low	High	non-Snr	Snr	non-Snr	Snr
Yes	18	1	7	0	8	1
No	39	21	16	3	17	14
	p<0.01		NS		NS	

A relationship between seizures at work and job status was found ($X^2=7.44$ $df=1$ $p<0.01$ $minEF=5.29$). Seizures at work were less likely to occur in high status jobs. However, there was no relationship found between the occurrence of seizures at work and seniority of nurses (Fisher exact $p=0.064$) or manual posts (Fisher exact $p=0.37$).

10.6.22 Disruption due to a seizure

Eighteen respondents gave an answer to the question of what happened after the latest seizure at work. Thirteen respondents (72%) said they were always able to carry on with their work. Five respondents said they always went home after a seizure.

Respondents were asked who was notified of their most recent seizure. The most common notification was to management; however, nearly a quarter of seizures were unreported to anyone. In only two cases was a seizure not witnessed by another person.

Table 10.19 Notification of most recent seizure

	Frequency (N=18)	%
Management & Occupational health	13	72
Casualty Department	1	6
No-one notified	4	22

There were five cases (13%) where a seizure occurred whilst in the presence of a patient. In all the other cases (fifteen respondents) the respondents were working but patients were not involved. Below is a list of the comments made by respondents about the work activities they were engaged in at the time of their seizures.

a) While in the presence of a patient

Nursing staff

"Washing a patient."

"Normal duties."

"Helping a patient undress, suddenly felt sick,
went to the ladies toilet and blacked out."

"Petit Mal seizure (while working) on the ward."

b) Circumstances unrelated to a patient

Manual staff

"Mostly about to give teas out."

"Cleaning ward."

"Carrying a chair at the time and I tripped over
a case which I didn't see."

"Working on switchboard."

Clerical staff

"Pulling notes for clinics, working in filing
room, preparing clinics."

"Working at my desk or just in the office."

"Clerical work."

Nursing staff

"Emptying bedpan/Having report."

"Listening to the report."

"Sitting in office writing ward report."

"I had just come on duty, had a warning, so sat
in the ward office."

None of these respondents reported injuries or
damage as a result of any on the most recent
seizures. See section 10.6.6 for more details on
accidents at work.

10.7 Main findings

The main findings from the NHS study are:-

- # There is no evidence of a consistent employment policy towards people with epilepsy in the London area. It would appear that different districts and indeed different hospitals within districts could enforce different rules concerning recruitment.

- # Age of onset was shown to relate to the reporting of career difficulties. Epilepsy onset during the training period was considered a particular problem due to the rigidity of the sickness absence rules [career blight]. However, there was no relationship between age of onset and seniority.

- # Senior nurses were significantly more likely than non-senior nurses to believe that their careers were affected by epilepsy.

- # Respondents were more likely to get the job of their first choice if they had epilepsy onset after joining the NHS.

- # A quarter of respondents reported seizures at work. These were significantly less likely to occur in high status jobs.
- # Seizure type was related to job status with significantly more respondents having a seizure pattern which included generalised seizures found in the low status jobs.
- # Respondents with uncontrolled seizures were not more frequently found in low status jobs.
- # Significantly more seizures at work occurred in low status jobs.
- # Most respondents reported that their colleagues' and managers' attitudes towards epilepsy were sympathetic. However, respondents in low status jobs were significantly more likely than chance to encounter negative reactions from both colleagues and management.
- # Respondents diagnosed as having epilepsy after joining the NHS were as likely to be in high or low status jobs. However,, respondents diagnosed before were significantly more likely than chance to be in low status jobs.

In this study it has not been possible to look for relationships with sickness absence or work performance; however, job status shown through the job titles of respondents has been used as the dependent variable. From this a number of observations lend support to and expand the findings from the Civil Service study.

The respondents were drawn from all areas of employment within the NHS. They were referred for having epilepsy and not for a health doubt or a health problem.

The seizures experienced by this group were mostly of tonic-clonic type. Almost half of the sample was seizure-free; over one third of those having active epilepsy said they got a warning prior to a seizure usually or always; the majority of the sample said their health was good or excellent; and nearly two fifths had late onset of epilepsy (after age 20 years).

Seizures at work were shown not to result in accidents and, despite some seizures occurring occasionally whilst working with a patient, minimal disruption to work was recorded.

Epilepsy was felt to be a hindrance to careers, especially for senior nurses. Some respondents had been told they could not do certain jobs in the NHS, although they had subsequently attained those jobs. Respondents who had epilepsy prior to joining the NHS were significantly less likely to get the job of their first choice than were respondents who had later onset.

Pre-employment diagnosis was shown to be a significant factor in job status. If onset of epilepsy occurred before starting work with the NHS, the respondent was more likely to be in low status jobs. Age of onset is shown to relate to feelings of career difficulties due to epilepsy. Although age of onset does not relate to seniority in nursing or management jobs. A critical period for onset is around sixteen years, which is the usual age of joining the NHS and of training. Onset during this period is likely to feel particularly disruptive to careers.

The attitudes of managers and co-workers were generally found to be sympathetic but there was a small minority of respondents who saw managers and co-workers as antagonistic. The negative attitudes could be demonstrated to occur more often in low status jobs.

It is interesting to note that uncontrolled seizures do not relate to job status, however seizures at work are significantly more often found in low status occupations. This suggests that seizures on their own are less of a problem than the timing or circumstances of the seizures. This is a possible reason for some of the ambiguity in the literature on the importance of seizures occurrence to employability.

PART 4

DISCUSSION AND CONCLUSIONS

Chapter 11	Discussion
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CHAPTER ELEVEN

DISCUSSION

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11.0 Overview

Part One of this thesis described the employment problems for people with epilepsy discussed in the literature. This led to the development of a biopsychosocial framework which has now been tested against empirical evidence. In this chapter I will discuss the findings from the studies reported in Part Two and relate these to the framework developed from the literature. Firstly I will deal with the employment problems that have been identified from the empirical work.

11.1 Employment problems for the individual

It should be stated at the outset that employment is not a major problem for most of the people with epilepsy who are currently employed and have their seizures under control. The recruitment study in the Civil Service demonstrated a wide range of occupations entered into by people with epilepsy and the NHS study demonstrated that people with epilepsy could be employed in a wide range of jobs and had acquired positions of responsibility and seniority. The empirical evidence demonstrates that epilepsy need not be a problem. However, it is found that there is a tendency to blame the epilepsy for failure to get promotion and a tendency to impose self-restrictions without consultation with the Occupational Health Service.

The empirical evidence also demonstrates that many people with epilepsy have been unemployed for long periods and that, once in employment, there can be difficulties in getting promotion and restrictions in the tasks undertaken. For people who are still having seizures, the problems are more acute, in that recent onset is shown to have a significant negative impact on sickness absence. Although this did not jeopardise employment in these organisations (except possibly where early retirement was taken), it could be a problem if

someone is in training at the time of the onset of epilepsy. The NHS study identified age of onset as a particular problem. The main problem for people with epilepsy once in employment is having seizures. If the employee has seizures then in order to maintain employment there must be a supportive environment in terms of, firstly, the attitudes of colleagues and managers, secondly, a work-place that can offer somewhere where seizures can occur without too much disruption and, thirdly, a flexible employment structure that allows the individual to take an increased level of sickness absence.

Let us look at the employment problems in more detail.

11.1.1 Unemployment

The experience of an employed population may be unrepresentative on the issue of unemployment. However, even in the Civil Service recruitment population it was noted that a high proportion of respondents had previously been unemployed for longer than three months and many had been unemployed for more than a year. This would seem to indicate a problem with gaining employment; however, it is noted that, without a rate for the

level of unemployment in the overall Civil Service recruitment population, conclusions cannot be drawn on this issue.

11.1.2 Blanket restrictions on tasks

From the Civil Service studies it was found that, in some cases, blanket restrictions have been placed on the activities of employees. The ambiguity of these restrictions was shown to be one of the particular concerns of the management referral group. Both managers and employees sought more information on the exact nature of the restrictions at work. It was noted that the criteria for the imposition of restrictions were not made clear in the records and that managers were concerned about this. It was also noted that there was no mention of standard periods of review, so that the restrictions were effectively imposed for the whole period of employment unless challenged.

11.1.3 Poorly defined career prospects

Judgement of career prospects made by the respondents themselves revealed some doubts about the possibilities of promotion. In the NHS group, nearly a quarter of the respondents felt that epilepsy had affected their careers and it was found that respondents were more likely to get the

job of their first choice if they did not have epilepsy at the time of recruitment. The highest level of career problems in the NHS study were felt by those whose epilepsy began between sixteen and twenty years. This is the age at which people are making career plans which affect their whole lives. Job goals and career plans set at this time will reflect the uncertainty that this onset period produces.

The problem here is not just the difficulty of arriving at precise guidelines and advice when the course of the epilepsy is unknown, but also having a structure within which to discuss the issues.

11.1.4 Inflexible sickness leave

Onset of epilepsy coinciding with training was a major problem. This was found in the NHS study, where respondents felt that nurse training courses had inflexible sickness absence rules resulting in dismissal from the course after only a short period of absence. Clearly, onset of epilepsy during training, education or at the beginning of a new job would be a serious problem where sickness absence rules are inflexible.

11.1.5 Limited job exposure

Restrictions in terms of tasks undertaken could affect career progression by limiting the exposure the employee has to work which is necessary for their chosen career path.

Limited job exposure comes about because of inflexible job structures and restrictions which are not tailored to the work place, the type of seizures and the task demands.

11.1.6 Stigma at work

The effects of stigma are given prominence in the literature. It is argued that the stigma attached to the label 'epilepsy' is likely to have a detrimental effect on the way people are perceived and therefore an effect on career prospects and employment generally. Evidence of stigma was looked for in all the studies reported here.

There was no indication of stigma found in the recruitment referral study but in the management referral study, managers commented that they expected adverse reactions from staff working with the person with epilepsy. They requested help in dealing with this. For discussion on the attitudes of managers and co-workers see section 11.2.18.

11.1.7 Employment advice

The literature indicates that employment advice is ambiguous and that as a result of this we might expect to find frequent examples of managers and employees seeking information on epilepsy and employment. From the empirical studies it was found that the need for clear information was a major problem area. In the management referral study, many of the referrals to the Occupational Health Service were attempts to clarify information and seek guidance on work practices. Requests for information were generated by both the manager and the employee.

The question was carried further in the NHS study, in which respondents were asked to state if they received information on jobs and, if so, from which source. Here it was found that employees received very little information or advice. Very few respondents had had information from the Occupational Health Service and the most frequently used information service had been voluntary agencies. This is important because, although the voluntary agencies may be producing very good information, they cannot possibly know the details of the individual's work situation or give advice that is anything other than very general employment information.

In the management referral study, nearly half of the referrals were managers seeking information on how to restructure jobs so that an employee with epilepsy could be fully employed and their career properly managed. Clearly, the co-ordination between medical advice and managerial need for information is problematic. Even where the medical advisor was familiar with the work of that department, as in the Civil Service, close attention to the work tasks is reliant upon both the manager and the Occupational Health Physician being able to communicate in the same terms and from a position of knowledge about the individual and the work-place. That this is a difficult area suggests that more needs to be done here to improve the co-ordination and information to management.

Having looked at the employment problems from the perspective of the individual with epilepsy, the next section will examine the issue from the perspective of the biopsychosocial framework in order to determine the reasons for problems occurring.

11.2 Testing the biopsychosocial framework

In this section I shall discuss the elements of the biopsychosocial framework in the light of the empirical evidence and with reference to the literature. It is worth repeating here that the selection process for the groups studied was different in each case and therefore it will be possible to draw different conclusions from each study. In the Civil Service there were two samples collected. The first was selected on the basis of prevalence of epilepsy within a recruitment population, identified from their own report on a health declaration form. The second Civil Service group was selected on the basis of being referred to the Occupational Health Service for either an occupational health problem or for advice. This group most closely represents a group of workers with epilepsy of whom an employer is most likely to be aware. This is the group which might be identified as 'a problem'. Unfortunately it is not possible to say what proportion this group represents of the whole population of people with epilepsy in the Civil Service, as total prevalence figures are not available.

The NHS group is again a sample of all known cases and could be viewed as the closest to the general population of workers with epilepsy. However,

as the sample was selected by the Occupational Health service using their own criteria, often on the basis of known cases, here again we may be looking at a population which, if not constituting a problem, are recognisable as people with a potential or previous problem. Bearing in mind that the people without a problem are the hardest to identify, I continue with the following discussion of the elements of the biopsychosocial framework.

Dependent variables

11.2.1 Type of job

The literature suggests that people with epilepsy will be restricted in their type of employment. It is also suggested that given proper precautions and attention to the type of epilepsy, there should be little need for people with epilepsy to be restricted. The question was asked as to whether people with epilepsy could be found in a variety of types of employment.

From the empirical studies we have seen that people with epilepsy were employed in a wide range of occupations. In the NHS study it was noted that employees with epilepsy were engaged in a wide

range of jobs which included management posts and had achieved senior status positions in nursing and manual posts. However, in the management referral study of the Civil Service it was noted that respondents tended to be grouped in the lower grade clerical posts. Management referral respondents were not found in grades above Executive Office and this suggests that either there are more problems at these grades because of the type of work or that people with epilepsy are not promoted above these grades.

Let us take one example from the management referral study to illustrate what may be happening generally. A customs officer was referred to the study because his manager wanted advice on the restrictions imposed on him due to his epilepsy. He had been restricted from working at heights which meant that he could not work on board ship to carry out 'rummage' duties. (This referred to searching for contraband within a ship, which might involve the use of gantries and ladders in order to carry out search activities adequately.) His job was restructured so that these duties were avoided and his new tasks involved more desk-based duties. However, it was not taken into consideration that in order to obtain promotion he would have to have experience of search

activities. He was therefore effectively restricted to his present post with no prospect of further career moves unless he left that part of the service. This was considered unsatisfactory by both the individual and the line manager; however the situation had not been encountered before and there was no set procedure to resolve the situation to the satisfaction of the employee or manager.

This then suggests that although people with epilepsy can be found in many types of occupation and would appear to be able to function adequately in these occupations, if a problem is identified there may be insufficient procedures to deal with it adequately and the individual may then be restricted in their career from that point onwards. This clearly suggests the need for more information and clear guidelines on how to restructure the working environment or the career path to include greater flexibility and allow people with epilepsy to participate more fully.

11.2.2 Work performance

The literature on this issue is contradictory, as some studies suggest that people with epilepsy will have poor work performance and others that they will have good or even above average work

performance. One problem in interpreting the findings has been the absence of a consistent definition of work performance; in some studies 'work performance' has referred more to sickness absence and in others to loss of work time due to accidents. It is difficult to obtain an objective measure of work performance which would increase the validity of the findings.

In the empirical work reported here, there were problems of obtaining objective information on work performance from the NHS study. In the Civil Service studies however, an objective measure of work performance was available. Here it was possible to check the personnel and management records for evidence of management warnings to the employee for poor performance. Very few indicators of poor performance were found in the recruitment referral study.

The frequency of work performance ratings for the management referral respondents were no different to that of other workers in the Civil Service. The high incidence of people being given warnings of poor performance in the management referral group is a reflection of the fact that group selection was partly dependent upon those warnings being issued. In other words, we cannot draw conclusions about poor performance being dependent upon other variables if poor performance is included as one of the criteria for selection of the sample. The variable cannot both be dependent and independent at the same time.

11.2.3 Sickness absence

From the Civil Service study it is found that lengthy sickness absence is taken by some respondents. However, this is found mainly in the management referral group, where the reason for referral was often the length of the absence and for employees with recent onset of epilepsy where lengthy sickness absence in the early stages may be unavoidable. Respondents who have recently started to have seizures had the greatest problems with sickness absence. It may be that these exceptional cases are perceived to be typical by

employers and hence engender the view that epilepsy results in high levels of sickness absence.

11.2.4 Shift work

From the literature it was indicated that shift work could be a problem for people with epilepsy and that shift work was generally advised against due to the possibility of this affecting the seizure pattern.

It was found that most of the respondents in these surveys were not doing shift work. However, in most cases the work undertaken was unlikely to have involved shift work. Where shift work was the normal pattern of work, as in the NHS, respondents were found to be doing shift work. These findings suggest that the reason why the literature concludes that people with epilepsy are not doing shift work is dependent upon the industry and not related to the presence or severity of the epilepsy.

11.2.5 Job restrictions

The literature showed that restrictions at work could be a major problem for people with epilepsy and the main reason for this was that restrictions were based on generalisations about epilepsy and

generalisations about the work undertaken. The studies suggested that restrictions to career movement were imposed on employees with epilepsy. The problem with the restrictions was that employees considered them to be ambiguous and unstated. This was partly due to all references to future restrictions being made in terms of the need to 'judge each case on its own merits'. This laudable principle is just as much a problem as blanket restrictions if the criteria upon which the judgement will be made are not clarified for the person with epilepsy.

Evidence of task restrictions were found for the respondents in the Civil Service study where, in the recruitment group, there were blanket restrictions imposed on a small number of people. There was no indication of the criteria upon which these judgements were made nor reference to review periods or criteria for lifting the restrictions. A much larger proportion of the management referral respondents had formal restrictions applied to them. These restrictions were again expressed in general terms, covering working alone, potential hazardous work, security issues and equipment use. However, in addition to the formal restrictions, it was also noted in this group that a large proportion of those respondents

who did not have formal restrictions imposed self-restrictions upon their activities. These restrictions were not based on formal advice from the Occupational Health Service. Given the limited amount of advice available on employment issues, these restrictions may in some cases have been in excess of what would be considered to be appropriate for them by the Occupational Health Department. This, then, could constitute a greater barrier to employment than restrictions imposed by employers.

The literature suggests that restrictions can be imposed too harshly and unnecessarily restrict work. The studies described in this thesis suggest that formal and informal or hidden restrictions exist which could affect current work and career progression.

Restrictions at work cannot be viewed as exclusively a dependent variable, although it is likely to be affected by the independent variables in the framework it is also likely to have an independent affect on job type and possible work performance and sickness absence. It therefore becomes possible to view it as a separate category.

11.2.6 Accidents at work

According to the literature, the possibility of an accident occurring due to a seizure is the most common reason for not employing someone with epilepsy. However, according to the surveys conducted here, there is no evidence that this need be the case. No accidents were reported in the Civil Service or NHS studies.

This is not to say that accidents are not of concern. That an accident occurs at all as a result of a seizure should be a worry to employers. It was shown from Chapter Six that the Health and Safety regulations applying to any business must consider that the employee with epilepsy must be placed in a work situation which will not put them at unnecessary risk.

There is a need here to look more fully at the type of working environments which can be considered safe. It is important not to restrict the person with epilepsy unnecessarily; however, it is also important not to go to the other extreme and take unnecessary risks. Advice must be available to the manager as to what are safe working environments. If managers are unsure

whether work places are safe for people with epilepsy then more precise information needs to be made available.

Independent variables

11.2.7 Seizure type

The literature gives a lot of attention to seizure type. It indicates that those people with seizures including generalised seizures are likely to have the most problems. From the medical records available for these studies it was unclear exactly who had mixed seizure patterns and who had exclusively generalised seizures; a measure of seizure type was therefore derived which distinguished respondents having seizure patterns including generalised seizures from those having seizure types excluding generalised seizures.

A direct relationship between seizure type and employment problems (excessive sickness absence or poor work performance) was not found. However, the NHS showed that seizure type could be related to job status, with more people in low status jobs having a seizure pattern which included

generalised seizures. It is concluded that seizure type will make a difference only in terms of job status.

The management referral study found 88% of the respondents with a seizure pattern which included generalised seizures. This is higher than the other studies by at least 15% and is significantly higher than the recruitment study. The presence of generalised seizures is, therefore to be found more often in employees with employment problems.

11.2.8 Incidence of seizures

In the literature it was found that there was contradictory evidence concerning the prospects of people who had active seizures. In some sources it was suggested that seizure frequency was not a factor; some people with quite frequent seizures could be found in employment without noticeable effect on their work performance or employability. In other sources it was said that placing people with active seizures was very difficult for the vocational advisor and that such individuals, if they were found jobs, were more likely to have only short employment periods. I therefore examined what is the relationship between frequency of seizures and employment variables. Here I took Rodin's point concerning methods of

calculating effect (see figure 3.1) and used the collapsed category of incidence of seizures rather than a breakdown into different frequencies, which is likely to obscure a real effect.

Seizure incidence was assessed in relation to sickness absence and work performance in the Civil Service studies. Both the recruitment study and the management referral study showed that there was no effect on work performance but there was an effect on sickness absence. Respondents having seizures took greater sickness absence. It would appear therefore that, as the literature suggests people with active epilepsy can be found in employment without loss of work performance. However, for the person to retain employment the work place must be tolerant of higher sickness absence levels.

If work placement is a problem for people with active epilepsy is there evidence that people are in different types of work. In the NHS study, incidence of seizures could not be seen to be related to job status. There was no statistical relationship between seizure frequency and high and low status jobs nor with seniority of nursing or manual grades. It may be difficult to place any

one individual with active epilepsy, however having active epilepsy does not define the job type of the individual.

11.2.9 Increasing frequency

It was suggested in the literature that employees with an increasing frequency of seizures were likely to have adverse work outcomes. In the empirical research reported here, employees with an increasing seizure frequency were only found in the Civil Service study and mainly in the management referral study. There was no indication in the management sample of an association with work performance for this variable nor of an association with sickness absence. It should be noted in a third of cases, employees with increasing seizure frequency were also people who had experienced recent onset of epilepsy and that the variation in sickness absence for this group is large. The empirical evidence would seem to suggest that the important underlying variable is recency of onset and not a varying frequency for people who have chronic epilepsy. Some further investigation of this variable is required.

11.2.10 Seizure auras

The importance of auras (warnings of seizures) was given little prominence in the literature.

However, it was suggested that a person who gets a regular aura may be better placed to obtain and retain employment. The question therefore was asked, are the people who are employed likely also to be the people who experience auras?

Auras were perceived before every seizure by between a quarter and a third of the respondents to each of the studies. This would appear to be a high figure and would confirm the view that warnings help people to maintain employment, however, a relationship could not be found with employment status in the NHS study and there was no significant difference between the management and recruitment samples on this variable. There is therefore no empirical support for this variable.

11.2.11 Recovery time

The length of recovery time from a seizure was also suggested as a possible factor in increasing the employability of someone with epilepsy. The empirical data showed that 'recovery' time varied between individuals, from a few seconds to more than one day. Approximately half of each sample had a recovery time of less than half an hour.

This figure is encouraging because they suggest that the amount of time lost due to seizures at work can be fairly minimal. Dividing the samples at the half hour point on the range it was not possible to demonstrate a difference in terms of work performance or sickness absence. There is therefore no empirical support for this variable.

11.2.12 Coincidental disorders

It has been widely reported in the literature that the problems reported with employment for people with epilepsy are based on case series which include people who have coincidental disorders in addition to epilepsy. Respondents in all the studies reported here were asked if they had other conditions in addition to their epilepsy. It was found that in the recruitment study of the Civil Service study between 22% and 33% of respondents had had a physical or mental disorder in the previous five years. The presence of this disorder however, did not relate to poor work performance or sickness absence. In the NHS study the question concerned other disabilities as opposed to the more general Civil Service question of illness and disability. In the NHS 15% of the respondents reported other disabilities. Here a comparison with low and high status could not be made due to

small expected frequencies however, it was found that co-incidental disabilities related to seniority in nursing grades.

We may conclude that the presence of co-incidental disabilities may have a negative impact on employment status but that it does not explain problems occurring at work. There is therefore some empirical support for the importance of this variable as predicted from the literature.

11.2.13 Factors precipitating a seizure

The question of what factors in the work place might precipitate a seizure has been poorly covered in the literature. Precipitating factors were not always apparent to respondents. From the empirical evidence it is found that different factors were important to each sample; for the recruitment group the two factors most often reported were not taking medication and lack of sleep; for the management and NHS samples the two factors were stress at work and lack of sleep. In the Civil Service studies all the factors were assessed for association with the dependent variables. Only one factor emerged as important; stress was found to be associated with the amount of total sickness absence taken.

Stress is mentioned by between a sixth and a half of all respondents. However, only one respondent, in the management referral sample, said that he would avoid stress at work because it might cause a seizure. It was least frequently mentioned by respondents from the recruitment sample.

VDUs and flashing lights were also seen as possible causes of seizures by many respondents. Around a quarter of each sample thought that this could be the cause of seizures. This is interesting, given that the literature shows that photosensitivity occurs in only two per cent of people with epilepsy (see section 5.10.1). People are clearly misinformed on this issue.

11.2.14 Drug side-effects

Adverse side-effects from medication have been identified as a possible problem area leading to difficulties at work. In the recruitment study, where there were the least employment difficulties, it was found that respondents did not refer to side-effects of medication. However, those respondents who stated that they were dissatisfied with their medication were significantly more likely to take greater total sickness absence.

In the management referral study and the NHS study, the issue of side-effects was raised as a problem. In the NHS study about a third of the sample referred to side-effects that they had experienced. In the management referral study, documentation was able to confirm that an inappropriate drug regimen had caused severe problems with work performance for one respondent and that once that medication had been optimised the employee was able to carry on work without difficulty. This therefore, illustrates the need to be careful of the drug regimen and to be aware that it can play a major role in the cause of problems at work.

11.2.15 Onset prior to employment

The literature suggest that age of onset of epilepsy may play a major part in the employment process. The surveys reported here have not been able to confirm this for a number of reasons. In the recruitment study, no relationship between age of onset and work performance or sickness absence could be identified. However, for the management referral group, age of onset was shown to be related to poor work performance ratings. Respondents with earlier age of onset were found to be receiving more warnings of poor work performance.

Comparisons to work performance ratings and sickness absence could not be made in the NHS study, however, it is noted that the age of onset was later than that found in the other studies. Here the median age was 19 years, with a large proportion of nurses having onset between 11 years and 20 years.

From this we can draw the conclusion that, although age of onset of epilepsy is not related to sickness absence, there is evidence that it is related to poor work performance. However, this conclusion is treated with caution as it is not found in all cases. The NHS study indicates that people with early onset are able to achieve senior positions and the recruitment study is unable to identify a relationship between age of onset and poor work performance.

11.2.16 Onset after employment

Post-employment onset of epilepsy was suggested as a possible problem area which had not been covered adequately in the literature. A few people with recent onset of epilepsy were found in the Civil Service and the NHS. In both studies, recent onset made a significant difference to the total amount of sickness absence taken. There was no relationship between recent onset and poor work

performance ratings in the Civil Service. However, it was noted that respondents with onset prior to NHS employment were more likely than chance to be found in low status jobs.

Onset after employment with the consequent time needed to achieve a suitable drug regimen is likely to disrupt career plans especially if onset occurs during training. It has been seen that nurses have particular problems because their teaching establishments have a rigid sickness absence period. Career choices made at the time of onset will also be detrimentally affected.

Mid-career onset, after the individual has become established in a job, would therefore seem to be less of a problem. Where the career is established, the person is likely to be able to take fairly lengthy periods of sick leave and still retain their position.

To this finding can be added the observation from the Civil Service documentary evidence that respondents who were identified for early retirement also tended to be in the late onset group (see section 9.4.3). This suggests that there may be a further career effect depending upon age of onset. Respondents with mid-career onset were likely to be able to continue their

careers whereas respondents with onset in late-career were likely to be seen as more of a problem and offered early retirement.

11.2.17 Behaviour at work

We saw in the literature the suggestion that people with epilepsy may have psychological problems as a result of having epilepsy or as a result of having the label epilepsy. Although there is no actual evidence for a personality difference, it would appear that this is still a part of the popular image of epilepsy.

Poor behaviour at work is a major reason for people with disabilities losing their jobs. The literature has not indicated that this is specifically a problem for people with epilepsy; however, because it relates to the question of employability it was considered worthy of investigation. In the Civil Service studies described here, it is possible to look at this issue through the personnel records of respondents, in which complaints from managers or co-workers would be recorded. Out of nearly one hundred people with epilepsy originally referred by management for advice only one recorded warning for anti-social behaviour was found. The likelihood of obtaining this result by chance

within a group of people reported to Occupational Health for employment problems is likely to be high. It can therefore be concluded that there is no evidence found for a relationship between epilepsy and anti-social behaviour at work.

11.2.18 Attitudes of managers and co-workers

It was shown that employees with epilepsy thought that mainly positive attitudes were expressed by their managers and colleagues. However, it was noted that a few managers and colleagues in the Civil Service were thought to view epilepsy as fearful. This factor could not be demonstrated to relate to work performance, the placement of restrictions or sickness absence. Negative attitudes were also recorded by one in six respondents in the NHS, these attitudes were all noted by respondents in low status jobs who saw negative attitudes in both managers and co-workers. However, although negative attitudes exist the overall attitude in the organisations examined was, seen by the respondents to be, positive.

11.2.19 Disrupted education

A factor which is taken up in the literature is the possible disruption to education by someone having epilepsy from an early age. It was

suggested that a disrupted education could be a significant factor in determining the employability of an individual. Respondents in the Civil Service and NHS studies were asked to indicate if they felt that epilepsy had effected their education or training. Between a quarter and two fifths of the respondents stated that they felt that their education had been disrupted because of epilepsy. There was no significant difference between the proportion of respondents in the management and recruitment samples who saw their education disrupted. It may be that a large proportion of any population, given a negative social label or chronic medical condition, will state that their education has been disrupted because of it.

11.2.20 Social support problems

It was suggested by the literature that social support could alleviate the effects of stigma, and an indicator of this would be if people with problems at work were also shown to be people with social support problems. A standard questionnaire which looks at social support needs was used in order to obtain information on this factor. The group with marked problems were not found to be significantly different from the rest of the sample in terms of poor work performance ratings

and sickness absence. However, if the Civil Service management referral group was used as an example of people with 'employment problems' it is found that these individuals were the most likely to have high levels of social support need. Indeed, the level was six times that of other respondents. Although this difference could not be tested statistically, if people with problems at work also have social support needs this must counteract the buffer effect against stigma (see section 4.13). Stigma then is likely to have a greater effect in this group.

11.2.21 Seizures at work

A common reason given by employers for not employing someone with epilepsy is the possibility of seizures occurring at work. The literature suggests that seizures at work may occur quite often. It was found in these studies that seizures were occurring at work for some people. However, no respondents in the recruitment referral sample had seizures at work. In respondents having employment problems (management referral sample), seizures at work occurred in half of the group. It was demonstrated that management referral respondents having seizures at work were not significantly more likely to take longer periods of sickness absence than other employees, did not

receive more warnings for poor work performance and did not have more restrictions placed upon them.

For the NHS sample one in four respondents had a seizure at work in the previous two years. It was found that seizures at work were significantly more likely to occur to respondents in low status occupations. This was not the case for the incidence of seizures in total, therefore seizures occurring at work have an independent impact on employment to that of having active epilepsy.

The empirical evidence confirms that there can be quite high levels of seizures occurrence at work amongst some employees with epilepsy. However, it should be noted that the two groups where this was found were also the groups which had been brought to the attention of the Occupational Health Service. This was the method of referral for the management referral group and, for the NHS group, it was also likely that the Occupational Health Service would identify employees with epilepsy through the occurrence of seizures at work. So, although seizures are occurring, it cannot be said that seizures at work are a general feature of the employment of people with epilepsy, this is indicated by the recruitment study, which suggests

that there is be a hidden population of employees with controlled epilepsy who do not come to the attention of the Occupational Health service. For a further discussion of the disruption to work caused by seizures see the next section.

11.2.22 Disruption due to seizures at work

In association with the question concerning seizures at work (see 11.2.21) we also have to ask what disruption is caused by seizures at work. Here, there was surprisingly little documentary evidence made available. Seizures occurred in many different circumstances but the majority of respondents were able to carry on working following the seizure.

Clearly, generalised or sudden seizures at work can result in disruption of work and this is shown in the NHS study. However, it is also seen that the incidence of problems is small in comparison to the number of seizures occurring.

11.3 Relationships within the framework

The following relationships are identified from the empirical work. The major dependent variables examined fall into two distinct categories - work-place problems (e.g. work performance, sickness absence) and long term career outcomes

(e.g. low job status). These two categories are found to have different relationships within the framework. Work-place problems are found to be significantly related the control aspects of epilepsy (e.g. occurrence of seizures, recency of onset of epilepsy) and social factors outside of work (e.g. social support needs). Whereas long term career outcomes are found to be significantly related to the characteristics of the epilepsy (e.g. seizure type, presence of other disability) and psychosocial factors inside work (e.g. attitudes of managers and co-workers). The only variable which is found to relate to both work-place problems and career outcomes is 'age of onset of epilepsy'. These relationships are shown by the solid arrows in figure 11.1.

As was discussed above 'restrictions' must be viewed as both an independent and dependent variable. The documentary evidence shows that employees were concerned that restrictions were imposing limitations on their careers. Therefore, although a statistical relationship was not proposed within the framework, it is apparent from the documentary evidence that one exists. It was also found that there were significantly more respondents with restrictions placed on them in the Civil Service management sample than the

recruitment sample and that the management sample was also taking significantly greater amounts of sickness absence. This then illustrates a link between work-place problems and restrictions. These relationships are shown in figure 11.1 by the shaded arrows.

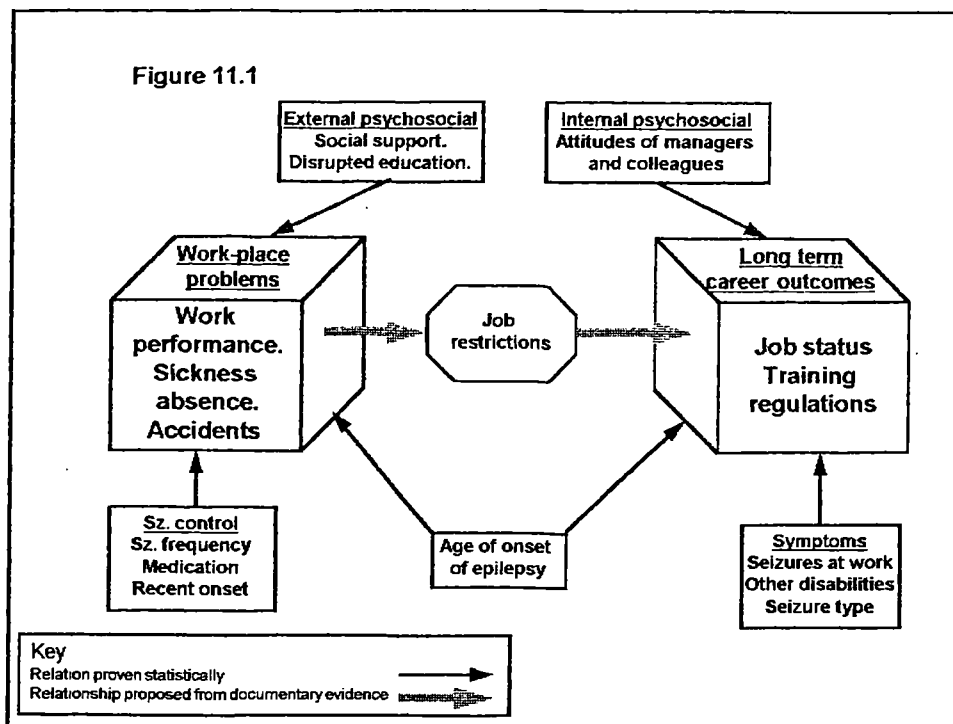


Figure 11.1 begins to explain the problem of epilepsy and employment. It illustrates some of the complexity of the environment within which the employee with epilepsy and the manager of the person with epilepsy have to operate. The empirical work and the above discussion also

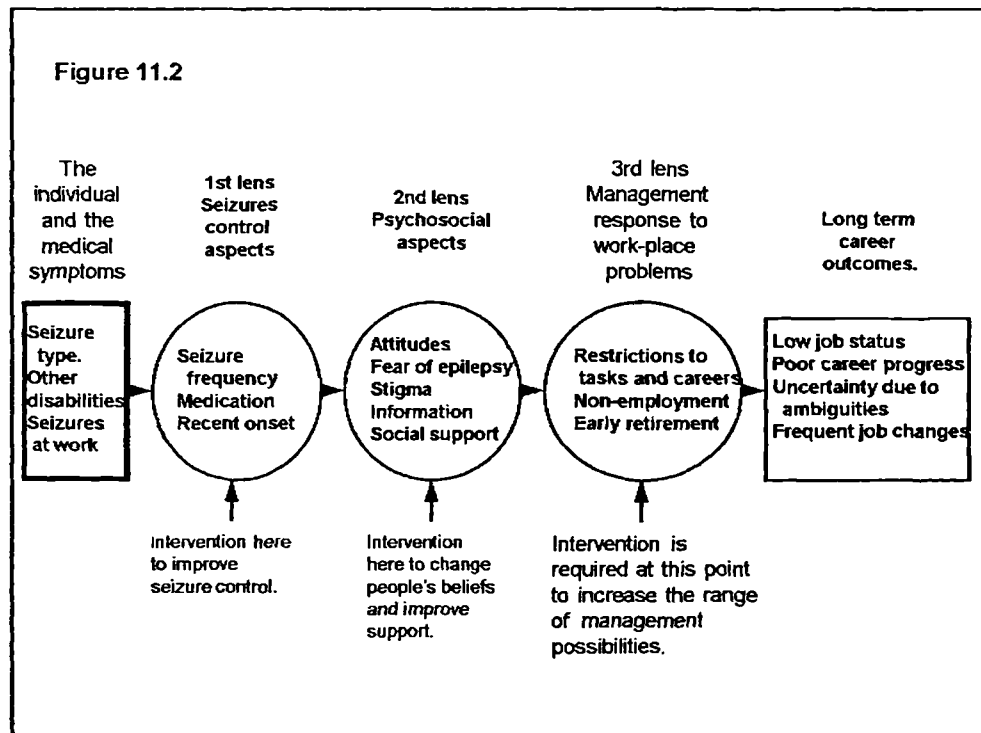
suggests that restrictions at work provide a link between work-place problems and long-term career outcomes.

The framework, thus far examined, has taken us part of the way towards explaining the systemic problems of epilepsy in the work-place and has illustrated the need for a biopsychosocial interpretation of outcomes. As it stands, however, we are unable to identify points of intervention or to establish a new research programme. However, further exploration and examination of the framework is likely to result in greater reductionism and ultimately little advantage to people with epilepsy or to their managers. In order to progress, it is necessary to develop a biopsychosocial model which will help us to intervene within the problem area. As was stated in Chapter One, in order to understand the problem of epilepsy and employment more fully we need to develop a model which will explain the issues and lead to suggestions for intervention. Following the literature review and the empirical work described above it is now possible to turn to the development of that model.

Intervention in the past has been in the form of improving the medical condition and improving the knowledge about and the image of epilepsy. From the foregoing analysis it can be seen that there are many elements which need to be taken into consideration if a full understanding of the problem is to be gained. From Part Two we have a framework of elements which must be considered. These have been examined in the light of the empirical evidence and we are now in a position to suggest a biopsychosocial model using these elements. This model uses the metaphor of filters or lenses to illustrate the view that problems in epilepsy and employment are caused by co-existing multiple factors. I shall adopt this type of model because its application allows us to identify where intervention can take place.

The analysis of the literature and the empirical evidence leads us to the view that, whatever the composition of the individual's epilepsy, the eventual outcome for the individual at work will be the result of an interrelationship between medical, psychosocial and occupational variables. How epilepsy is perceived in the work-place will depend on the presence and the relative strengths

of these elements. The image of epilepsy at work is, then, focused by aspects of the working environment as if they were lenses focusing a light beam. This can be illustrated using the model in Figure 11.2.



The individual is seen here as the person plus the symptoms of the epilepsy and other medical conditions. These symptoms are part of the history of the individual e.g. have seizures occurred at work and what type of seizures occurred. To this it must be possible to add knowledge of past reactions. These are aspects of the individual and

his condition which remain true, and act as the object upon which the lenses focus. The first lens is the current reality of epilepsy. This is composed of the seizure control aspects which have an impact on the work-place problems; this is the objective reality of the presence of epilepsy at work. The second lens is composed of the subjective beliefs about epilepsy held by managers and colleagues; these are derived from society's view of epilepsy. This lens is reliant upon beliefs which need not be accurate but are widely held. No matter what the objective evidence, the second lens can present a false image of epilepsy.

The third lens is composed of the management actions that are taken in the work-place to accommodate seizures or the possibility of seizures. This is another layer of cultural information about epilepsy. Given the premise that actions influence beliefs, it follows that, if all possible actions are negative, then this must engender negative attitudes and beliefs about epilepsy. As we saw with the history of epilepsy in Chapter Two, when there was no useful practical and objective description of epilepsy, false beliefs (myths) emerged to explain seizures. We can see that this dynamic is also occurring at work: where the only actions to be taken are

negative, then attributions about people with epilepsy must also be negative. Epilepsy is therefore viewed through the lens of the management response.

Where there have been unsatisfactory outcomes for people with epilepsy, the model suggests that the image of epilepsy has been badly focused by these three lenses.

Looking at epilepsy as a human resource problem, we can see that management will view epilepsy through these lenses. What the manager sees is a complex phenomenon which could have serious consequences in the work-place. In order to intervene, the manager must make some response to this complexity. However, the options available are very limited (see the next section). What then has been done to improve the situation for people with epilepsy? From Figure 11.2 it can be seen that intervention, so far, has been directed towards the first two lenses. In other words, attempts to improve the control of seizures are attempts to intervene at the first lens, and attempts to create a more realistic image of epilepsy are aimed at the second lens. The problem as illustrated by this model, however, suggests that there is a third point for intervention and

epilepsy are aimed at the second lens. The problem as illustrated by this model, however, suggests that there is a third point for intervention and that is to improve the management response capability. Let us now take a look at the strategy needed for intervention.

11.5 A strategy for intervention

Given the complexity of epilepsy in relation to work and given that management is unlikely to have the knowledge or expertise to match that complexity, then the problem for people with epilepsy can be explained as a management resource problem of matching this complexity.

This can be explained from the basis of known theory. We have already learned from Chapter five that the complexity of the management response and the complexity of the environment must be matched for any system to function (the law of requisite variety). This will be done either by reducing the level of complexity of the situation by, for instance, not employing the person with epilepsy, or by increasing the variety of responses available to management in other words broadening the number of options available at the third lens. Responses tend to be the following: restricting

either covertly or overtly with the result that people with epilepsy will be underemployed, have frequent job changes, or be unemployed. Reducing the level of complexity is an option which can perhaps be seen all too frequently occurring. The surveys indicate that people with epilepsy experience high levels of unemployment, they were given early retirement and blanket restrictions on tasks undertaken were widespread. These, then, are illustrations of an attempt to reduce the complexity of the situation by removing the cause of the complexity. An illustration of an attempt at the second alternative (broadening the options) can be found in the Civil Service, where line managers can be seen to be actively seeking greater information concerning their role in the employment of someone with epilepsy. They are thus attempting to increase response capacity in order to match the complexity of the situation.

Problems occur, for the second alternative, when this information-seeking does not result in the increased complexity required. Judging from the reactions found in the records, the information received was often ambiguous and required further explanation. It was apparent that managers were often not happy with the advice they received because it did not provide the level of control

they needed with reference to particular individuals. In other words, it did not allow them to match the complex demands of the situation.

The problem seen in terms of a human resource management approach, and set within the findings of this study, is to provide an alternative which the manager is happy with and which does not unnecessarily restrict the person with epilepsy. This suggests intervention in four areas, as follows:

- 1) Increase the autonomy of the line manager in dealing with epilepsy. This will encourage the process of making decisions based on the needs of the work unit and on the needs of the individual. One way of doing this would be to have the line manager and the individual brought into the debate about appropriate criteria for restrictions, so that they can feel a part of the decision making process.

- 2) Improve information flow to policy makers. This will decrease the possibilities of ambiguous information and advice being offered. A standard job analysis structure could be implemented so that managers and Occupational Health staff can communicate within the same structure. Likewise,

the links and monitoring procedures should be improved so that breakdowns in communication do not occur.

3) Improve management techniques by providing training on disability management. This should include objective methods of ability assessment, methods of matching people to jobs, and how to manage stigma in the work-place.

4) Develop a structure for the analysis of problems. This may be done by developing a shared understanding of risk between the Occupational Health Staff, management and the employee. In addition, a structure for the analysis of the restrictions, with strict review points or milestones will help the individual and the manager to assess restrictions and question their usefulness in the light of changing circumstances.

CHAPTER TWELVE

CONCLUSIONS

Contents

12.1	Conclusions
12.2	Practical issues in the work-place
12.3	Future research
12.4	Meeting objectives of the thesis
12.5	Contributions to knowledge

12.1 Conclusions

In this final Chapter, I want to identify the conclusions to be drawn from the thesis and state how these have met the objectives set in Chapter One.

The problem to be researched was that of epilepsy and employment. This was investigated from two standpoints: firstly, a major literature review was undertaken in order to examine all aspects of the problem; secondly, two organisations with three occupationally based populations of people with epilepsy were surveyed.

The conclusions to be drawn from this work are that the problem of epilepsy and employment cannot be looked at from a single perspective. It is medical, social and psychological in its nature.

The problems for people with epilepsy at work must be seen as emerging from the interaction of the various elements which make up the concept of epilepsy and cannot be pinpointed to any one variable.

The empirical evidence showed that having frequent seizures did not necessarily result in unsatisfactory employment outcomes. It was shown that high levels of sickness absence were always found in people with recent onset and that having seizures at work also led to greater amounts of sickness absence than seizures occurring outside of work. Where seizure were generalised high levels of total sickness absence and epilepsy related absence were found. This has implications for Occupational Health Departments who should be aware that the recruitment of people with active epilepsy need not be a problem if the seizures occur outside working hours and are not generalised.

The empirical evidence also showed that work performance was acceptable even where seizure frequency was high. People with seizures at work could not be shown to have inferior work performance nor could it be demonstrated that seizures at work significantly increased accidents

or injuries. The presence of auras before a seizure and short recovery times following a seizure may help in maintaining employment and this is suggested by the high frequency of these factors in the populations studied. Therefore, it can be said that epilepsy does not constitute an employment problem, in terms of work performance, for the majority of people with the condition.

Factors which work against employment were identified to be the presence of coincidental disorders, side-effects from medication, early and recent onset of epilepsy. Stress was found to be of concern to several respondents but not the majority. Career changes as a result of onset of epilepsy were likely to occur if onset coincided with training or during the early part of career development. Career disruption was least likely if epilepsy occurred during mid-career but epilepsy onset in later career was shown to result in early retirement. Therefore health advisors must be aware of the importance of the timing of onset for individuals and the possible effects on careers. It is worth considering providing training for the individual in how to present their epilepsy to their employer or manager. Fewer problems will arise if the manager and the employee start with an informed and shared knowledge of epilepsy.

The perceptions of people with epilepsy are important. People with early onset epilepsy perceived that there had been problems with their education. Employees with epilepsy also showed that they felt ill-informed about the restrictions on their employment and about what impact epilepsy would have on their careers. It was also noted that some people felt that very negative attitudes were expressed towards them by managers and colleagues. Therefore, where this occurs, counselling and access to information, needs to be improved. Nonetheless, employers need to be aware that negative reactions are not inevitable.

It was found that generalised restrictions were imposed on employees and that, as a result, the individual themselves and management needed to be better informed about the criteria used when applying restrictions. It is suggested that standard review periods need to be established. These will reassure both the employee and the employer that monitoring of precautions is being undertaken and that precautions imposed are necessary. In addition, it was found that there were three issues related to restrictions: restrictions on tasks in present job; hidden or ambiguous restrictions to career movement; and (possibly the most restrictive of all)

self-imposed restrictions. All three issues pointed to the need for more informed advice to be made available.

Given the diversity of the elements and their interrelatedness, the issue of epilepsy and employment must be described by a biopsychosocial model. A model employing a series of lenses has been used to encompass these elements and illustrate the outcomes for people with epilepsy at work. This model proposes that there are a number of filters or lenses that can distort the image of epilepsy available to the manager. From the documentary evidence it is concluded that managers are active in their attempts to seek better information and increase the possibilities of good management in relation to epilepsy. From the discussion of why this is not often possible, it has been suggested that positive intervention could take place in a number of areas. These have been identified as: the autonomy of line managers to deal with employment and epilepsy issues; their training on disability management; and the information available to them about epilepsy. Positive intervention is also possible by developing a methodology for better and more structured communication between management and Occupational Health.

12.2 Practical issues in the work-place

The practical issues in the work-place identified from this thesis can be put into to four areas related to: the person with epilepsy; the manager of the person with epilepsy; the organisation and the medical profession.

The person with epilepsy must be aware of:

- # the restrictions that are placed on them and seek clarification where these are ambiguous;
- # the need to obtain advice on employment from the Occupational Health service;
- # their abilities and limitations in relation to work;
- # the need to clarify information to others about epilepsy.

The manager will feel more confident about the employment of someone with epilepsy if they:

- # have access to information on epilepsy and employment;
- # are able to identify the abilities of the individual which are not affected by the epilepsy;
- # improve the communication between themselves and the Occupational Health Service;

- # have the ability to restructure the working environment to accommodate the needs of the person with epilepsy;
- # are reassured that people with epilepsy need not be a significant problem at work.

The organisation must be:

- # able to tolerate greater sickness absence from someone with active epilepsy, especially if they have recent onset of epilepsy;
- # made aware that insurance and health and safety regulations need not stand in the way of employment of people with epilepsy;
- # aware of the damaging effect of stigma and how to manage employees' attitudes.

The medical professions must be aware that:

- # they are possibly the only source of information on employment that the person with epilepsy is likely to actively encounter and therefore must be able to advise people on employment choices;
- # they may need to provide training to the individual in how to present epilepsy to an employer.

It has been proposed in this thesis that the neglected and main avenue for future intervention is to improve the possibilities of a positive management response to epilepsy. In this way it is possible to influence beliefs through actions. Therefore, research is needed ultimately to test this relationship in different circumstances but firstly to determine what and how positive management responses can be applied. If managers are to be targeted for intervention, more research is needed into their response to epilepsy and the options open to them. One approach to this may be through the work of Stafford Beer and the ideas of the Viable Systems Model (see 5.3). The application of this model would introduce a management approach and is appropriate to this research because it is a systemic approach which concerns the process of monitoring and control of organisations.

The following areas should also be examined in order to further explain and expand the relationships within the biopsychosocial model.

12.3.1 Survey of management response to epilepsy

It has been concluded in this thesis, from the application of the lens model, that managers are active in their exploration of methods to deal with the problem of epilepsy in the work-place. However, we do not know in detail what attempts are being made or the goals set by managers for these actions. A detailed and qualitative survey should be conducted in various organisations into how managers respond to epilepsy. This may illustrate examples of negative and positive reactions.

12.3.2 How organisations learn about epilepsy

The method by which organisations and individual departments learn about epilepsy and its management needs to be investigated. In order to improve the employment prospects of people with epilepsy, we need to identify how information is managed by an Occupational Health Service and how this information is presented to the policy-making and control aspects of the organisation. It may be that new methods of presenting information are required. One method might be an expert system that guides the manager through the occupationally relevant aspects of epilepsy and aids in the identification of appropriate management.

12.3.3 The development of management techniques

One possible positive approach to management of people with epilepsy at work is to improve methods of job design and career structure. So that people with epilepsy are not unnecessarily excluded from critical career experiences. Managers need to be able to question whether, in objective terms, a person with epilepsy should be restricted in the fulfilment of that task and how these restrictions will affect outcomes for the individual and the organisation.

Job design and analysis systems could also provide a framework for Occupational Health to identify review points and establish criteria for restrictions. A standardised structure (list of activities applicable to all jobs) is unlikely to be useful but if the process were standardised it would mean that the communication between the manager and the Occupational Health Department could be improved and it would help the manager and the employee with epilepsy to structure questions and identify missing information, thus reducing ambiguity.

12.3.4 Employment presentation skills for epilepsy

We have seen that there is significant disruption to employment if there is recent onset of epilepsy, and I have concluded that in order to avoid problems at work there may be a need to train people with recent onset how to present their epilepsy to employers. Research is needed to look at how this can be achieved and what are the techniques which are likely to produce the best results. We also need to know at what stage the training should be given and how the employer should be approached.

12.3.5 A European study of epilepsy and employment

It was noted from the literature that epilepsy was treated differently in different countries. There is a great deal to learn from other countries about how they deal with the problem of employment for people with epilepsy. Given the possibilities for the open movement of workers across Europe, there will be pressure for increased harmony of treatment of disabled workers in the European states. A European study of the problems encountered in employment and the solutions offered by each state will provide a forum to discuss standards across Europe.

12.4 Meeting the objectives of the thesis

A critical analysis of the literature has been completed. This has examined the relevant material published on epilepsy and employment. The problem areas have been identified and assessed.

A framework for empirical analysis was described which considered the medical, psychosocial and occupational variables relevant to the problem area.

Two organisations employing people with epilepsy were surveyed. These surveys described the composition of this element of the work-force and related their experiences to the literature.

Through the surveys, this thesis has been able to identify the boundaries of the problem of employment for people with epilepsy at work, enabling a better definition of the problems encountered and exploration of the reasons for the problems.

The causes of problems are:

i) work-place problems are significantly associated with the seizure control aspects of epilepsy and psychosocial factors outside of work,

ii) long-term career problems are significantly associated with the symptoms of epilepsy and other disabilities, including if seizures occur at work and psychosocial factors inside of work.

The empirical work has been set within a biopsychosocial model that illustrates a systemic view of the development of problems for the individual. The model also indicated intervention points that can help to improve the situation for people with epilepsy at work.

Through this analysis, epilepsy is viewed as a human resource problem and the need for positive techniques in the management of people with epilepsy at work is seen as critical both to reducing negative outcomes but also to improving attitudes within an organisation.

In practical terms intervention is required in order to provide management with information about: how epilepsy relates to employment, and how communication can be improved between the individual, management and Occupational Health. The exploration of the model from a management perspective has been discussed in terms of the needs for future research.

This thesis has critically examined the variables proposed in the literature as relevant to the issue of epilepsy and employment and it has proposed a biopsychosocial framework. The studies have described the experiences of a wide variety of people with epilepsy in employment. This is a group which had previously not been adequately represented in the literature. The studies have demonstrated that there are two distinct types of employment problems, these being work-place problems and long-term career outcomes. It has been demonstrated that these are affected by different dynamics, and it has illustrated how these can be explored. The thesis proposed a biopsychosocial model that takes a systemic view based on the empirical work and builds on the literature.

The thesis identifies a critical point of intervention which has been overlooked in the literature. That being the improvement of management techniques for the employment of people with epilepsy.

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APPENDICES

Contents

1. The Questionnaire
- 2 Social Support model

Reference No.....

CIVIL SERVICE EPILEPSY STUDYHOW TO COMPLETE THE QUESTIONNAIRE

- * Wait until you have a whole hour alone to spend on the questionnaire
- * Please answer the questions by putting a ring around the number next to your answer or by writing in the spaces provided
- * If you would like to write a note of explanation at any question, please do not hesitate to do so
- * If a question is not appropriate to your circumstances, place a tick in the box provided and move on to the next question
- * Where dates are requested and you cannot recall the exact day, then please be as accurate as possible
- * It is very important to answer all the questions
- * When completing the questionnaire, answer each question in turn before moving on to the next. Do not leave a question to be answered later.
- * If you have recently left the Civil Service, please complete for the period prior to your departure.

IF YOU HAVE NEVER HAD EPILEPSY - PLEASE TICK THIS BOX AND RETURN

☐

IF YOU HAVE NOT TAKEN UP EMPLOYMENT WITH THE CIVIL SERVICE

- PLEASE TICK THIS BOX AND RETURN

☐REHABILITATION RESOURCE CENTRE

Department of System Science
The City University
Northampton Square
London EC1V 0HB

MEDICAL QUESTIONNAIRE

STRICTLY CONFIDENTIAL

This questionnaire is concerned with medical matters and covers your general health and a description of the seizures you have had in the past. We are also interested in the type of medical care you have had and if you have ever had any seizures at work. Please complete every question by placing a ring around your answer. Exact dates are useful but approximate dates or amounts are also of value.

SECTION I GENERAL HEALTH AND MEDICATION

Please ring one number after
each appropriate answer

Q1 How would you describe your health generally?

Excellent	1
Good	2
Fair	3
or Poor	4

Q2 Have you had, during the last 5 years, any physical or nervous illness or disability apart from epilepsy?

Yes	1
No	2

Q3 If yes, please specify the illness, disability or infirmity: *

.....

Q4 Are you taking any drugs other than for epilepsy?

Yes	1
No	2

If yes, please specify which drugs:

.....

.....

Q5 Are you taking an oral contraceptive pill?

Yes	1
No	2
Not applicable	3

SECTION 2

EPILEPSY

Please ring one number after
each appropriate answer

Q6 Apart from the collection of prescriptions or check-ups for work, when was the last time you consulted your GP and/or hospital specialist about epilepsy?

	General Practitioner (GP)	Hospital Specialist
Less than 6 months ago	1	1
Between 6 and 12 months	2	2
Between 1 and 5 years	3	3
Longer than 5 years	4	4
Never	5	5

Q7 Do you now consider yourself to be seizure free?

Yes	1
No	2
Uncertain	3

Q8 How long ago was your last seizure? Give date if known

Q9 At what age did you have your first MAJOR seizure?

Q10 At what age did you have your first MINOR seizure?

Q11 At what age was epilepsy first diagnosed?

Q12 How frequently did MAJOR seizures occur in the last 12 months?

More than once per week	1
One or two a month	2
One or two every six months	3
One or two in the last year	4
None in the last year	5
Never had a major seizure	6

SECTION 2 Continued...../

Please ring one number after
each appropriate answer

Q13 How frequently did MINOR seizures occur in the last 12 months?

More than once per week	1
One or two a month	2
One or two every six months	3
One or two in the last year	4
None in the last year	5
Never had a minor seizure	6

Q14 How long after having a seizure can you carry on with what you were doing?

A few seconds	1
A few minutes	2
Up to half an hour	3
30 minutes to an hour	4
Between 1 and 3 hours	5
More than 3 hours	6

Q15 How often do you get a warning prior to a seizure?

Always	1
Usually	2
Sometimes	3
Never	4

Q16 Does this warning usually allow you to do any of the following:

Stay at home	1
Go somewhere safe or secluded	2
Warn the people around you	3
Not enough time to do any of these	4
Not applicable	5

SECTION 2 Continued...../

Q17 Do seizures occur only during sleep?

Yes 1

No 2

Q18 Do seizures occur only within a few minutes of waking?

Yes 1

No 2

Q19 Do seizures ever result in falling?

Yes 1

No 2

Q20 Have seizures been associated with any of the following?

Alcohol or its withdrawal 1

TV or flashing lights 2

Stress at home 3

Stress at work 4

Lack of sleep 5

Not taking medication 6

If other, please specify:

_____ 7

Not known to be
associated with anything 8

Q21 Has any other member of your family had epilepsy?

Yes 1

No 2

If yes, please state their relationship to you (mother, sister, etc)

SECTION 3

SICKNESS ABSENCE

FOR THOSE WHO HAVE BEEN IN THEIR PRESENT JOB MORE THAN 12 MONTHS

Tick if not applicable
and go to question 23☐

Q22 How much time have you had off work due to epilepsy in the last 12 months?

FOR THOSE WHO HAVE STARTED THEIR PRESENT JOB WITHIN THE LAST 12 MONTHS

Tick if not applicable
and go to question 24☐

Q23 How much time have you had off work due to epilepsy since you started this job?

FOR THOSE IN A JOB FOR 12 MONTHS PRIOR TO STARTING THEIR PRESENT JOB

Tick if not applicable
and go to question 25☐

Q24 How much time have you had off work due to epilepsy in the 12 months prior to starting your present job?

Q25 If not working at the moment, is this due to:

Retirement at age 60 or 65 1

Medical retirement 2

Sick leave 3

Dismissal 4

Resignation 5

Other, please specify:

 6

Not applicable or on holiday 7

What was the date of your last working day?

/____/19____

SECTION 4

MEDICATION FOR EPILEPSY

FOR THOSE TAKING DRUGS FOR EPILEPSY

Tick if not applicable
and go to Section 5

☐

Q26 Which of the following drugs do you take for epilepsy?

Dosage

Phenytoin (Epanutin)	_____	1
Phenobarbitone	_____	2
Primidone (Mysoline)	_____	3
Sodium Valproate (Epilim)	_____	4
Carbamazepine (Tegretol)	_____	5
Ethosuximide (Zarontin)	_____	6
Other, please specify:	_____	7

Q27 Have the blood levels of the drug been measured?

Yes	1
No	2

If yes, please give the date they were last checked:

...../...../19.....

Was the medication altered:

Yes	1
No	2

Q28 Have you had side effects which might be due to these drugs?

Yes	1
No	2

Q29 If yes, please specify:

.....

.....

Q30 Are you satisfied with your present medication?

Yes	1
No	2

SECTION 5

SEIZURES AT WORK

FOR THOSE WHO AT ANY TIME IN THEIR WORKING LIFE HAVE HAD A SEIZURE AT WORK

Tick if not applicable
and go to Section 6

☐

Q31 . Did any of these seizures result in injury to yourself?

Yes 1

No 2

Q32 Did any of these seizures result in injury to anyone else?

Yes 1

No 2

Q33 Did seizures occur while working?

Yes 1

No 2

SECTION 6

IF YOU WISH, PLEASE USE THE SPACE BELOW TO EXPAND ON ANY INFORMATION YOU HAVE
GIVEN ABOVE.

SOCIAL SUPPORT QUESTIONNAIRE

STRICTLY CONFIDENTIAL

This questionnaire is about your social circumstances, the questions are of a standard format and are used for comparison purposes only.

SECTION 1

Please indicate which of the following apply to you:

Q1
Male 1 Female 2

Q2
Married/co-habiting 1 Divorced/separated 3

Widowed 2 Single 4

Q3 What was your age last birthday?

Q4 Do you own or rent the accommodation in which you live?

Own 1

Rent from council/local authority 2

Rent from a housing association 3

Rent from a private landlord 4

Other, please describe 5

Q5 Who else lives with you at home?

Husband/wife 1

Children aged under 16 2

Children aged 16 or over 3

Other relatives 4

Other non-relatives 5

No-one else in the household 6

Q6 How many children do you have?

Q7 Are you registered disabled with the Job Centre?
(ie do you have a green card?)

Yes 1

No 2

SECTION 2

Please answer all the questions which apply to you by drawing a ring around the number under your answer. Where the questions do not apply to you, please indicate with a tick in the area provided. These questions are of a standard format and are used for comparison purposes only.

A. Housing (everyone answer)

Q8 Are your housing conditions adequate for your and your family's needs?

Adequate	Slightly inadequate	Markedly inadequate	Severely inadequate
1	2	3	4

Q9 How satisfied are you with your present accommodation?

Satisfied	Slightly dissatisfied	Markedly dissatisfied	Severely dissatisfied
1	2	3	4

B. Work (everyone answer)

Q10 How satisfied are you with your present job?

Satisfied	Slightly dissatisfied	Markedly dissatisfied	Severely dissatisfied
1	2	3	4

Q11 Do you have problems getting on with any of the people at your work?

No problems	Slight problems	Marked problems	Severe problems
1	2	3	4

FOR HOUSEWIVES WITH A FULL OR PART TIME JOB OUTSIDE THE HOME

Tick if not applicable ☐

Q12 How satisfied are you with working and running a home?

Satisfied	Slightly dissatisfied	Markedly dissatisfied	Severely dissatisfied
1	2	3	4

FOR THOSE WHO ARE NOT WORKING (retired, unemployed, or off sick)

Tick if not applicable ☐

Q13 How satisfied are you with this situation?

Satisfied	Slightly dissatisfied	Markedly dissatisfied	Severely dissatisfied
1	2	3	4

SECTION 2 Continued..... /

C. Financial Circumstances (everyone answer)

Q14 Is the money coming in adequate for you and your family's needs?
 Adequate Slightly Markedly Severely
 inadequate inadequate inadequate

1 2 3 4

Q15 Do you have any difficulties in meeting bills and other financial commitments?
 No Slight Marked Severe
 Difficulties difficulties difficulties difficulties

1 2 3 4

Q16 How satisfied are you with your financial situation?
 Satisfied Slightly Markedly Severely
 dissatisfied dissatisfied dissatisfied

1 2 3 4

D. Social Contacts (everyone answer)

Q17 How satisfied are you with the amount of time you are able to go out?
 Satisfied Slightly Markedly Severely
 dissatisfied dissatisfied dissatisfied

1 2 3 4

Q18 Do you have any problems with your neighbours?
 No problems Slight Marked Severe
 problems problems problems

1 2 3 4

Q19 Do you have any problems getting on with your friends?
 No problems Slight Marked Severe
 problems problems problems

1 2 3 4

Q20 How satisfied are you with the amount of time you see your friends?
 Satisfied Slightly Markedly Severely
 dissatisfied dissatisfied dissatisfied

1 2 3 4

Q21 Do you have any problems getting on with close relatives?
 No problems Slight Marked Severe
 problems problems problems

1 2 3 4

Q22 How satisfied are you with the amount of time you see your relatives?
 Satisfied Slightly Markedly Severely
 dissatisfied dissatisfied dissatisfied

1 2 3 4

SECTION 2 Continued.... /

E. Marriage and Boyfriends/Girlfriends

FOR ALL THOSE WHO ARE MARRIED OR HAVE A STEADY RELATIONSHIP

Tick if not applicable ☐

Q23 Do you have any difficulty confiding in your partner?

No difficulties	Slight difficulties	Marked difficulties	Severe difficulties
1	2	3	4

Q24 Are there any sexual problems in your relationship?

No problems	Slight problems	Marked problems	Severe problems
1	2	3	4

Q25 Do you have any other problems getting on together?

No problems	Slight problems	Marked problems	Severe problems
1	2	3	4

Q26 How satisfied are you with your relationship?

Satisfied	Slightly dissatisfied	Markedly dissatisfied	Severely dissatisfied
1	2	3	4

Q27 Have you recently been so dissatisfied that you have considered separating from your partner?

No	Sometimes	Often	Yes, planned or recent separation
	2	3	4

FOR ALL THOSE WHO ARE NOT MARRIED/DO NOT HAVE A STEADY RELATIONSHIP

Tick if not applicable ☐

Q28 How satisfied are you with this situation?

Satisfied	Slightly dissatisfied	Markedly dissatisfied	Severely dissatisfied
1	2	3	4

SECTION ? Continued.

F. Domestic Life

FOR THOSE WITH CHILDREN UNDER 18

Tick if not applicable ☐

Q29	Do you have any difficulties coping with your children?			
	No difficulties	Slight difficulties	Marked difficulties	Severe difficulties
	1	2	3	4

Q30	How satisfied do you feel with your relationship with your children?			
	Satisfied	Slightly dissatisfied	Markedly dissatisfied	Severely dissatisfied
	1	2	3	4

FOR THOSE WITH CHILDREN OF SCHOOL AGE

Tick if not applicable ☐

Q31 Are there any problems involving your children at school?			
No problems	Slight problems	Marked problems	Severe problems
1	2	3	4

FOR ALL THOSE WITH OTHER ADULTS LIVING WITH THEM

(including relatives but excluding spouse) Tick if not applicable ☐

33' Do you have any problems about sharing household tasks?			
No problems	Slight problems	Marked problems	Severe problems
1	2	3	4

Q33	Do you have any difficulties with the adults in your household?			
	No Difficulties	Slight difficulties	Marked difficulties	Severe difficulties
	1	2	3	4

Q34	How satisfied are you with this arrangement?			
	Satisfied	Slightly dissatisfied	Markedly dissatisfied	Severely dissatisfied
	1	2	3	4

G. Legal Matters (everyone answer)

Q35 Do you have any legal problems (custody, maintenance, compensation, etc)?				
No problems	Slight problems	Marked problems	Severe problems	
1	2	3	4	

SECTION 2 Continued.

For those who are living alone:

Tick if not applicable ☐

Q36 Do you have any difficulties living and managing on your own?

No Difficulties	Slight difficulties	Marked difficulties	Severe difficulties
1	2	3	4

Q37 How satisfied are you with living on your own?

Satisfied	Slightly dissatisfied	Markedly dissatisfied	Severely dissatisfied
1	2	3	4

1. Other (everyone answer)

Q38 Do you have any other social problems or problems?

No problems	Slight problems	Marked problems	Severe problems
1	2	3	4

If so, please specify:

EMPLOYMENT QUESTIONNAIRE

- * Some of the questions in this part of the questionnaire can be quite difficult, please answer every question

STRICTLY CONFIDENTIAL

JOB DIAGNOSTIC QUESTIONNAIRE

This part of the questionnaire concerns your work and your feelings towards that work. Please circle the number which is next to the answer you wish to give. It should be possible to answer all the questions, however, if you get stuck, move on to the next and then come back to the ones you have missed.

SECTION 1

Please enter your job title, department and length of service in that job:

Q1 Job Title

Q2 Department Location

Q3 How long have you had your present job title?

Q4 How long have you worked in the Civil Service?

Q5 What were you doing immediately prior to starting your present job?

Working for another organisation 1
please specify job title:

Working in the Civil Service 2
please specify job title:

Unemployed 3

Other, please specify: 4

Q6 For how long were you doing the above?

Q7 How many companies or organisations have you worked for in the last 24 months?

Civil Service only 1

Civil Service plus one other 2

Civil Service plus two others 3

More than two other companies 4

Q8 How much time have you spent unemployed (unable to find work) in the last 24 months?

SECTION 1 Continued...../

Q8 What is the longest time you have been unemployed between jobs?

1 to 4 weeks	1
1 to 3 months	2
3 to 6 months	3
6 to 12 months	4
Over 1 year	5
Never	6

If you have been unemployed, when was this? _____

Q9 Have you attended any of the following?

6th form	1
Further Education College	2
Polytechnic	3
University	4
Vocational or practical skills courses	5
Apprenticeships	6

Q11 Please list any qualifications obtained (CSEs, 'O' & 'A' levels, degrees etc):

Q12 Do you feel that you require more training to do your present job?

Yes	1
No	2

Q13 Has epilepsy ever been a problem to you during your education or training?

Yes	1
No	2

SECTION 1 Continued.....

Q14 Have you ever had to change jobs or lost a job due to epilepsy?

Yes	1
No	2

Q15 Have you ever had any careers advice related to epilepsy from any of the following?

Manpower Services Commission's Disablement Advisory Service	1
Social Workers	2
Voluntary organisations	3
Job Centre	4
Social Service Careers Dept	5
Others, please specify:	6
None received	7

Q16 Has epilepsy restricted your choice of travelling in any of the following ways?

Prevented from obtaining a driving licence	1
Prevented from travelling alone	2
Other - please specify:	3
No restrictions	4

Q17 Does epilepsy influence the method used to travel to work?

Yes	1
No	2

Q18 Do you hold a current driving licence?

Yes	1
No	2

SECTION 1 Continued...../

- Q19 Does your present job involve any of the following?
- | | |
|----------------------------------|---|
| Shift work | 1 |
| Working with dangerous machinery | 2 |
| Driving duties | 3 |
| Working alone | 4 |
| Working at dangerous heights | 5 |
- Q20 Due to epilepsy, have you avoided any of the following in your choice of work?
- | | |
|----------------------------------|---|
| Shift work | 1 |
| Working with dangerous machinery | 2 |
| Driving duties | 3 |
| Working alone | 4 |
| Working at dangerous heights | 5 |
| Other, please specify: | 6 |
-
- Q21 Does your manager/supervisor know about your epilepsy?
- | | |
|-----|---|
| Yes | 1 |
| No | 2 |
- Q22 Do your fellow workers know about your epilepsy?
- | | |
|-----|---|
| Yes | 1 |
| No | 2 |
- Q23 Which of the following phrases best describes the attitudes of your manager/supervisor towards epilepsy?
- | | |
|-------------|---|
| Sympathetic | 1 |
| Unconcerned | 2 |
| Exaggerated | 3 |
| Fear | 4 |
- Q24 Which of the following phrases best described the attitudes of your fellow workers towards epilepsy?
- | | |
|-------------|---|
| Sympathetic | 1 |
| Unconcerned | 2 |
| Exaggerated | 3 |
| Fear | 4 |

The social aspects of epilepsy was covered by one section of the questionnaire which concentrated on the nature of social adjustment. A 'social problem questionnaire' was used which was similar to that to the General Health Questionnaire in respect of mental ill-health and was developed at the General Practice Research Unit of the Institute of Psychiatry in London. It is a self-report research tool designed to "screen individuals particularly at risk for manifesting social maladjustment and/or dysfunction". The questionnaire is aimed at obtaining a reasonable estimate of the respondents' social and personal satisfaction with life in general.

The questionnaire is composed of the following subject areas:-

Housing	Adequacy of housing. Satisfaction with housing.
Occupation/ social role	Satisfaction with job / social role Problems with personal interaction with workmates.
Finance	Satisfaction with financial situation
Social relation- ships	Satisfaction with ability to get out. Problems with neighbours. Problems of personal interaction with friends Satisfaction with amount of time seeing friends.
Relatives	Problems of personal interaction with relatives. Satisfaction with the amount of time seeing relatives.
Marital role	Marital status. Difficulties of confiding with partner. Sexual problems. Satisfaction with relationship. Possibilities of separation. Satisfaction with not having a partner. (for those who do not have a steady relationship)
Children	Difficulties in management. Satisfaction with relationship. School problems.

Domestic Relation- ships	Problems of managing household. Satisfaction with domestic relationship. (other household members excluding spouse/children)

Legal matters Problems with these matters.

Living alone	Difficulties in the management of living alone. Satisfaction with living alone.

(R. H Corney and A. W. Clare, Self-report
questionnaire to identify social problems,
Psychological Medicine, 1985, 15, 637-649)

Scoring system

The scoring system adopted was that used by Corney and Clare (1985). The 31 questions are grouped into the 11 categories above. The subject is then classified as having a problem in that category if he/she indicates a marked or severe difficulty or dissatisfaction on one or more of the items within that category. Marital satisfaction was shown as being less sensitive than the other categories and for this reason the answers were recorded and the total score for each subject found. A major problem in this area was indicated by a response of 4 or more.