AN EVALUATION OF CREST, A NIGHT HOSPITAL FOR ELDERLY PEOPLE SUFFERING FROM DEMENTIA

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DECLARATION

I hereby declare that whilst registered as a candidate for the degree of Doctor of Philosophy with the University of London, I have not been a registered candidate for another award of the University of London, nor of any other University.

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ABSTRACT

The aim of the study was to evaluate the effectiveness of a night hospital nursing service for elderly people suffering from dementia; in particular, to establish the appropriateness of night support for this group and their carers. The study developed as a result of previous work that demonstrated that some carers requested "in-patient" admission for their relative/friend because of the stress of providing support and supervision at night.

The research methods involved an evaluative structure - process - outcome, quality assurance and case study approach. An operational policy for the service was drawn up, as were nursing standards (process). The service was evaluated over a two year period. Patient outcomes were measured using a visual analogue scale at intervals over six months to identify behavioural changes. Similarly, carers' feelings of anxiety and coping ability relating to their caring role were measured. Changes in patient behaviour and carer anxiety and felt ability to cope were analysed using the Wilcoxon matched-pairs signed ranks test.

Carers were interviewed to elicit the effects their relatives' attendance at CREST had on their day to day lives. Changes in the use of community care services as a result of CREST were also identified. The sample consisted of 38 patients and their informal carers.

Nursing activity was observed using non-participant observation to establish both the type of activity and peak work load periods.

The results demonstrate that CREST had a positive outcome in terms of supporting patients' carers and that patients' behaviour did not change significantly while attending the night hospital. This latter result has been interpreted as a positive outcome in that people suffering from dementia can be expected to deteriorate over time.

In conclusion it is anticipated that the results of this study have significance for planning nursing services for the care group involved and should assist in identifying the number and grade of staff needed to deliver optimum care at night to elderly people with dementia.

Recommendations for changes in the operational policy have been made which will assist managers in planning new services.

The research suggests that new nursing services for this group in the health authority will be more closely related to the individual needs of patients and their carers than has been achieved hitherto. This strategy should lead to fewer patients needing long term in-patient care.

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CHAPTER 1

INTRODUCTION AND BACKGROUND

This chapter describes the background to the study. The reasons for developing a night hospital nursing service for elderly people who suffer from dementia are discussed and the importance of providing respite for carers explored. The thesis presents a structure, process and outcome evaluation of the night hospital service referred to as CREST; Care and Respite of Elderly people with Support and Treatment.

1.1 Origins of the night hospital nursing service - CREST

Population predictions indicate that the number of people aged over 80 years living in Britain will increase substantially during the next twenty years (OPCS, 1991; Tinker, 1981). This group, commonly referred to as the "very old" are more likely to develop dementia than any other sector of society (Copeland et al, 1987; Ineichen, 1987). People who suffer from dementia frequently require assistance to fulfil their activities of living because they become confused, forgetful and physically frail (Gilleard, 1984; Lishman, 1987; Mace et al, 1985).

The majority of elderly people who suffer from dementia are cared for at home by a relative or friend (Copeland et al, 1987; Gilleard, 1984; Kay et al, 1970; Mace et al, 1985). When carers need assistance with supporting people with dementia, at home, community nurses have traditionally taken responsibility for providing help, particularly with personal care tasks (Baker et al, 1987; Bond and Carstairs, 1982; Isaacs et al, 1972; Luker, 1979; Vetter et al, 1984). Day hospitals and day centres provide a service for elderly people who suffer from dementia while giving carers a break from the responsibilities of caring (Bergmann et al, 1983; Smith and Cantley, 1985).

In addition residential respite care is provided by health authorities and social services to relieve caregivers for longer periods (Bergmann et al, 1983; Gilleard, 1984; Nolan and Grant, 1992). The mixed provision of home nursing services, day care and residential respite care may be insufficient for some families involved with supporting an elderly person with dementia at home (Alzheimer's Disease Society, 1991, Bergmann et al, 1983; Gilleard, 1984; Twigg, 1993; Watkins, 1987a).

Caring at home can be particularly difficult at night if the elderly person suffering from dementia becomes increasingly disorientated and agitated towards the end of the day (Armstrong-Esther and Hawkins, 1982; Barker and Mutterness, 1988; Cameron, 1941; Lishman, 1987; Mace et al, 1985; Paiva, 1990; Watkins, 1987a). Night time disturbance, wandering and the disrupting effects of the 24-hour need for supervision compound the difficulties of caring (Grad de Alarcon and Sainsbury, 1968; Greene et al, 1982; Mace et al, 1985; Sanford, 1975). Day care does not necessarily provide relief at appropriate times for carers who support a person requiring 24-hour care (Alzheimer's Disease Society, 1991; Gilleard, 1984; Levin et al, 1989; Smith and Cantley, 1985; Watkins, 1987a). This problem is illustrated by one spouse carer who reported:

> "I am offered day hospital care, at the times when I can best cope. What I need is to have a break at night. If only my husband could go out regularly once or twice a week at night, I could catch up on sleep. Then he wouldn't need to go in for respite care every month." (Watkins, 1987a)

In the same study a daughter who supported her mother was specific about her requirement for her evening and night care. She explained that her teenage daughters were reluctant to bring friends home in the evening, because of their grandmother's confusion and incontinence, which caused family friction. This carer said:

> "If my mother could go out for at least an evening a week, we could have a family meal, invite guests, be a real family. Without her interfering all the time." (Watkins, 1987a)

This carer said she wanted to continue to support her mother at home but that it would be impossible unless she got help for the periods when her children were at home. She pointed out that day hospital care and school hours were almost concurrent, except during holiday periods. Clearly she required relief from caring at completely different times from those offered by the day hospital service.

Night sitter services are reported to be successful in providing relief to carers who require assistance with looking after a relative or friend with dementia (Rosenvinge and Dawson, 1986; Twigg et al, 1990). However, in a study conducted by the author some carers, whose relatives were using the day hospital, wanted a night service outside their homes (Watkins, 1987a). Carers reported appreciating having time to themselves and privacy when their relative was at the day hospital. The implication was that the presence of a sitter would not give them the same degree of personal freedom within their own homes. The idea of the CREST service evolved as a direct result of carers describing the advantages and disadvantages, to them, of their relative or friend using day hospital and in-patient facilities.

The number of elderly people living in the geographical area served by the health authority in which CREST operated was considered. The health authorities prediction from the 1981 census figures was that there would be 20,770 people aged over 65 years living in the geographical area served by that health authority by 1987 (OPCS, 1985; Greater London Council, 1983)(Table 1.1).

AGED	NUMBERS	SEX RATIO %
65 - 75	11,460	48.6 men
75 - 79	4,410	
80+	4,890	51.4 women
	TOTAL: 20,760	

Table 1.1 Estimated population in geographical area served by a London Health Authority for 1987

If a conservative estimate of the prevalence of dementia in this population were calculated at 1% of people aged under 75 years and 5% of those aged over 75 years it was predicted that by 1987 approximately 580 people would have dementia in the geographical area served by the authority.

The increase in the elderly population and the identified need for night services to support carers of people with dementia led to the decision to introduce CREST in a London Health Authority in January 1989. The service was experimental in that it was only funded for a period of two and a half years, while an evaluation was conducted. It was intended the results of the evaluation would be used by managers to make decisions about its long term viability.

This thesis reports the way in which the service developed, the methods used to evaluate the service and the results of that evaluation. In addition, the recommendations made to the health authority based on the results of the evaluation are described and the decisions that were made concerning longer term provision are presented.

1.2 Review of previous literature

In Chapter 2 literature concerning dementia is reviewed, specifically that on Alzheimer's disease and multi-infarct dementia, because they are the most common forms to present in people over 60 years of age. Current social policy is then examined in relation to elderly people with dementia. The rise in the number of elderly people living in Britain, the increased prevalence of dementia with age and the current emphasis on community care is discussed. There is a need to develop new flexible community based nursing services for people with dementia and those who care for them at home.

The issues concerning being an informal carer of an elderly person with dementia is examined in Chapter 3. The nature of caregiving is discussed from an instrumental perspective and the interpersonal dynamics which can occur between carer and recipient are described. Motivation for undertaking the caregiving role and the benefits and costs of caregiving are explored. Caregiving is time consuming and both physically and emotionally demanding. The burden of caring can result in carers experiencing stress which can be the result of poor quality caregiving. Nursing services for elderly people with dementia should help caregivers to identify how they could be helped to cope better or even to relinquish the principal caring role. Carers are themselves legitimate clients for nursing services as well as the demented client.

The literature reviewed in Chapters 2 and 3 indicated that the CREST service should try to fulfil two aims. The first was to provide optimum nursing care to patients. The second was to work collaboratively with carers, to both promote continuity or patient care and to identify how the service might best be structured to relieve carers themselves. Literature concerning the way in which other community based services have been structured to meet similar aims forms the focus of Chapter 4. Emphasis on supporting carers and enabling them to cope with caring appeared to be the hallmark of a successful service. These results were partly attributable to the fact that most of the studies reviewed took a carer rather than a patient perspective. This is understandable, given the inability of many people who have dementia to describe the services they would most appreciate. Despite the difficulty in collecting information from patients with dementia patient outcomes should, it is argued, form a central focus in the evaluation of the CREST nursing service.

Chapter 5 contains a review of the literature relating to the responsibility of managers in setting parameters within which good nursing practice can take place. The application of a quality assurance cycle in nursing is discussed and the importance of defining structure, process and outcome standards explored. The relative merits of organising care delivery using task, team and primary nursing methods are illustrated. The functions of nursing models for nursing elderly people are examined with particular reference to the Roper et al (1980) activities of daily living model. The issues of grade mix and staff development opportunities are explored in relation to the quality of care delivered to patients. It is argued that managers have a key role in providing an organisational framework which facilitates clinical nurses in providing high quality nursing care for patients and their carers.

1.3 Research design and methods

The research design and methods are presented in Chapter 6. The evaluative design described contained two stages. The first involved defining the structural and process standards for CREST before the service opened. A framework containing an activities of daily living approach to patient care combined with a stress reduction orientation to supporting carers was devised for nursing practice at CREST. The second stage of evaluation, which involved data collection once CREST had opened, is presented in detail.

1.4 Results and discussion

In Chapters 7, 8 and 9 the results of the evaluation are presented. The first of these chapters details the changes that were made to the operational policy and the nursing standards for practice within the first year of CREST's operation. In addition data obtained from observing nursing staff activity and retrospectively reviewing nursing care plans of patients is presented. Chapter 7 is descriptive and illustrates the extent to which CREST nurses used the identified framework for nursing practice. Analysis and conclusions concerning the quality of nursing at CREST are presented in relation to the patient and carer outcome data in Chapters 8 and 9.

Chapter 8 details patients' activity and outcomes during the first 18 months of CREST's operation. Thirty four patients attended during the period reported. Patient outcomes are presented and the possible reasons for those outcomes are explored. The results of observing patients are discussed and the extent to which patient outcomes may have been attributable to the nursing process at CREST are evaluated.

Chapter 9 presents the results of carer interviews. Twenty seven carers were interviewed within one week of their relative or friend's first attendance at CREST. Carers were re-interviewed at subsequent intervals over a one year period. The material collected at interview was used to establish the effects on carers of their relative's or friend's attendance at CREST. Information concerning changes in the use of community services by patients and their carers resulting from the use of CREST are also examined in Chapter 9.

The final chapter of the thesis presents a critical discussion of the evaluation of the CREST service. The relationships between carer motivation, the problems experienced by patients and the framework for care at CREST are explored. It describes the actions that the mental health unit involved with CREST has taken concerning future provision of night nursing services for elderly people with dementia. Conclusions concerning the results of the evaluation are drawn and recommendations for future practice are made.

CHAPTER 2

DEMENTIA AND SOCIAL POLICY

2.1 Introduction

When planning the CREST night hospital the prevalence of dementia was considered together with the symptomatology of the disease processes involved in order to structure appropriate nursing provision. Appropriate provision was perceived in two ways: first, to ensure sufficient availability of the service within the organisational constraints imposed (including revenue and building allocations) to meet estimated demand; and secondly, to assist in planning a nursing service which would meet individual client needs.

It is impossible to plan any nursing service adequately without understanding the pathology associated with the illness from which clients suffer (McFarlane, 1977). Similarly, it was important to examine the provision of health and social care for people suffering from dementia and their families within the context of social policy decisions formulated by central and local government.

When planning any new health care provision those involved need to consider not only the financial cost of initiating the service, but also the likelihood of longer term revenue costs being met by either state and/or private contributions (Ham, 1992). It is impossible to conduct such an analysis without examining the political and economic factors which influence decisions regarding revenue for such services.

2.2 Dementia - definition, prevalence and incidence

In 1981 the Committee on Geriatrics of the Royal College of Physicians of London defined dementia as follows:

> "Dementia is the global impairment of higher cortical function, including memory, the capacity to solve the problems of day to day living, the performance of learned perceptuo-motor skills, the correct use of social skills and control of emotional reaction, in the absence of gross clouding of consciousness. The condition is often irreversible and progressive." (p.8)

This definition is all embracing, describing global deterioration of cerebral function and indicating the effect this physiological change has on sufferers' capacity to survive, in terms of meeting their own needs.

Dementia is a term given to nearly 100 different diagnoses in which cerebral function is impaired, but only two categories, Alzheimer's disease and multi-infarct dementia (MID), are commonly diagnosed in elderly people (Bergmann et al, 1983; Henderson, 1983). Recently, Alzheimer's disease, when initially presenting in a person aged 65 years or over, has been termed senile dementia of the Alzheimer type (SDAT) (Lishman, 1987).

The majority of dementia disorders occur in later life (Lishman, 1987), although AIDS related dementia is increasing in the younger population (Katona, 1989). The problems and symptomatology of dementia disorders in elderly people form the focus for this section of the literature review.

There is considerable disagreement regarding the prevalence of dementia in elderly people, with particular difficulty being experienced in the identification of mild cases (Henderson, 1990; Ineichen 1987, Jorm et al 1987, Lishman 1987). A review of 30 studies conducted in 13 countries, in populations over the age of 60 years, published between 1970 and 1987, demonstrated a variation in prevalence of between 2% and 24% (Ineichen, 1987). This variation can be attributed largely to the different techniques of identification, particularly for mild dementia, and the sampling frames used. It has been argued that a more useful estimate of prevalence could be made by examining the data from 18 surveys published between 1964 and 1984, which revealed a prevalence of severe dementia between 1% and 7% in people aged over 65 years (Ineichen, 1987).

There is some indication that more recent surveys suggested a reduced prevalence compared to earlier work. This may be due to more rigorous definitions of dementia and advances in the treatment of hypertension, thus reducing the incidence of multi-infarct dementia, although these suggestions were unconfirmed (Bergmann et al, 1983). That the prevalence of dementia rises with advancing chronological age is indisputable (Ineichen, 1987, 1989b; Jorm et al, 1987; Lishman, 1987; Royal College of Physicians, 1981). Pooled data from several cross-sectional surveys indicated that between 5% and 7% of the populations examined over the age of 65 years had dementia, with prevalence rates rising from about 2% in people aged between 65 and 70 years, to approximately 20% of those aged around 80 years and over (Royal College of Physicians, 1981).

A more recent community survey conducted in Liverpool used the computer assisted diagnostic procedure for dementia (AGECAT) which resulted in more reliable data than previous work based on individual medical diagnoses (Copeland et al, 1987). The AGECAT study revealed that 5% of the randomly selected sample (n=1070) of people aged over 65 years displayed levels of organic disorders sufficient to warrant a diagnosis of dementia (Copeland et al, 1987). The same study reported a linear relationship between the prevalence of dementia and chronological age in people aged between 65 and 80 years, with 12% of the group aged over 80 years displaying symptoms.

The Liverpool study (Copeland et al, 1987) supported the findings of Kay et al (1964), who found a prevalence of 5% in a similar community study conducted in Newcastle upon Tyne (n=758). When sub-clinical symptoms or mild organic brain syndromes were also counted, the prevalence rose to 10% (Kay et al, 1964), which matched the rate found by Copeland et al (1987) even though the two studies were separated by nearly 20 years. Both studies omitted hospital patients but, because 95% of the total elderly population live in their own homes or residential care settings (OPCS, 1991), any underestimation of prevalence was considered relatively small.

The extent to which the prevalence of dementia varies according to region is uncertain (Henderson, 1990; Ineichen, 1989b; Jorm et al, 1987). A comprehensive review of 47 prevalence studies conducted between 1975 and 1985 indicated that regional differences existed and that, in particular, the prevalence of SDAT and multi-infarct dementia varied according to region (Jorm et al, 1987). Similar results were reported in another review (Ineichen, 1987).

Ineichen (1987) calculated that a reasonable estimation of international prevalence would be 1% of the population aged 65-74 years, and 10% of people aged over 75 years. In Britain, the similarity of findings in the Liverpool study using AGECAT (Copeland et al, 1987) and the Newcastle upon Tyne survey (Kay et al, 1964), both of which had relatively large samples, indicated that a figure of 5% in the over 65 age group was the most accurate prevalence rate of dementia established in the British population to that date. The prevalence rose exponentially with age from approximately 1% at the age of 65 years to more than 10% between the ages of 80 and 90 years (Jorm et al, 1987).

Calculation of the incidence of dementia from patients' records is impossible because it is not a recordable disease, no registers on new cases are kept, and hospital in-patient records provide scant information since few sufferers warrant hospital admission. Incidence studies are expensive and time-consuming to conduct and so research into the field is also limited (Henderson, 1990). The most recent reported study involving a five year follow up of a total population found an annual incidence rate of 1% in the over 65 age group and 2% in people over the age of 85 years (Jagger et al, 1989).

Prognosis

Data on life expectation of people suffering from dementia is inconclusive because its insidious onset makes the precise date of diagnosis difficult to estimate (Burns and Levy, 1992; Gilleard, 1984; Jacques, 1992). Both patients and their relatives may have difficulty in recounting exactly when symptoms first occurred

(Jacques, 1992; Mace et al, 1985). Community studies suggest that there is a higher mortality rate among people with dementia when compared with the rest of the population (Copeland et al, 1992; Jagger et al, 1989; Kay et al, 1970; Maule et al, 1984).

Of particular interest to this study is the recent work conducted by Burns and Levy (1992) in South East London, which has a population similar to the neighbouring health authority in which CREST was developed. Environmental factors within the two health districts are also comparable in terms of housing, access to health care and socio-economic factors. One hundred and seventy eight people suffering from SDAT, with a mean age of 80.4 years, were included as a convenience sample recruited from hospital wards, day hospitals, day centres, Part III Homes, out-patients and through the medical domiciliary referral system. At three year follow up 47% had died, an overall standard mortality ratio of 3.5. This mortality rate is lower than described in some other studies which have tended to include patients suffering from both MID and SDAT (Burns and Levy, 1992).

Two other factors which may have affected the results were the inclusion of a higher proportion of community based patients in comparison with previous studies, and the rigorous methods of assessing clients to establish whether or not they were suffering from SDAT before they were included. The results suggested that the features of deterioration in people were advanced age, longer duration of illness, poor cognition, observable depression and presence of physical illness (Burns and Levy, 1992). These factors were supported by the presence of advanced cerebral disease as demonstrated by CT scan. All these factors needed careful consideration when planning CREST. Nursing care should be concerned with reducing aberrant behaviour, providing physical care and comforting patients to minimise mental distress.

The Burns and Levy (1992) study concentrated on patients with SDAT, but CREST planned to offer a service to elderly people suffering from both MID and SDAT. Therefore, further work on prognosis relating to both types of dementia is examined.

The length of time between admission to institutional care and death for people diagnosed as having dementia is one indicator of prognosis. Studies conducted in this area revealed a variation from one year (Cooper, 1987) to seven years (Diesfeldt, 1986), this variation is probably attributable to the severity of disease in individual patients on diagnosis (Ineichen, 1989b). A review of longitudinal studies led Christie (1985) to conclude that people suffering from dementia are now living longer than previously. With the advent of screening and early treatment for hypertension associated with MID, increased longevity could be anticipated. The picture is obviously complex, but it is possible to conclude that most patients diagnosed as having dementia are unlikely to live longer than seven years (Burns and Levy, 1992; Gilleard, 1984; Ineichen, 1989b; Kay, 1962; Lishman, 1987). The prevalence of any disease is related to the incidence rate, the size of the population at risk, and the prognosis of the disease (Adelstein et al, 1986). It has been demonstrated that knowledge concerning incidence rates and prognosis of SDAT and arterio-sclerotic dementia in elderly people is tentative.

The only anticipated rise in the number of elderly people in the population over the next 20 years is in those aged 80 years and over (Grundy, 1986; OPCS, 1991; Tinker, 1981). It has been estimated that this group will increase between 1989 and 2009 from 2.1 million to 2.6 million people (OPCS, 1991). If the prevalence of dementia is at least 10% in this age group a rise of approximately 50,000 people over the age of 80 years suffering from dementia in Britain can be expected (Copeland et al, 1987; Ineichen, 1987; Kay et al, 1964). The population aged between 65 and 79 years is projected to remain at approximately 7 million over the same period (OPCS, 1991). If a very conservative estimate of a 1% prevalence of dementia is applied to this population and combined with the estimated increase in people over the age of 80 years, a figure of approximately 330,000 sufferers can be anticipated by 2009.

2.3 Senile dementia of the Alzheimer's type

Computed tomography (CT) has enabled doctors to define the pathology of Alzheimer's disease (Burns and Levy, 1992; Jacques, 1992; Lishman, 1987). The cerebral hemispheres shrink and lose weight mainly in the cerebral cortex with damage to nerve cells (Burns and Levy, 1992; Jacques, 1992). The extent of damage to cells is still difficult to discern, but microscopic investigation suggests that there is degeneration of nerve endings and connections resulting in senile plaques and neuro-fibrillary tangles (Burns and Levy, 1992; Jacques, 1992; Wischik, 1989). The shrinkage of cerebral hemispheres, particularly in the parietal, temporal and frontal lobes, probably causes mood changes, confusion and acute delirium with which most patients present at some time (Jacques, 1992; Lishman, 1987). Behavioural disturbances including aggression, wandering and incontinence appear to be associated with particular areas of atrophy at CT scan (Burns and Levy, 1992).

More females than males present with SDAT, but the difference in incidence is related not to sex but to the greater longevity of women compared to men (Jorm et al, 1987). The mean onset of the disease has been estimated at the age of 73 years in men and 75 years in women (Larsson et al, 1963). The accuracy of this finding is questionable because the onset can be hard to identify, probably because it runs a fairly protracted course (Gilleard, 1984; Ineichen, 1989b; Jacques, 1992; Lishman, 1987). The onset of SDAT is usually insidious and can be viewed as gradual failure of the brain (Burns and Levy, 1992; Jacques, 1992; Lishman, 1987). Initially, individuals present with failing memory, lack of initiative and interest and an exaggeration of previous traits, such as egocentricity and obsessional behaviours. Patients with SDAT display cognitive, behavioural and physical symptoms at some time during the progression of disease (Burns and Levy, 1992; Jacques, 1992; Lishman, 1987; Rabins, 1990; Royal College of Physicians, 1981).

Cognitive symptoms include disintegration of intellect, lack of initiative and interest and memory loss (Burns and Levy, 1992; Lishman 1987). Initially short term memory is affected, but as the disease progresses the patient may forget large periods of his/her life (Burns and Levy, 1992). This distressing symptom is attributed to the presence of neuro-fibrillary trangles in the hippocampal neurones (Royal College of Physicians, 1981). Many patients become disorientated in time and place in varying degrees (Burns and Levy, 1992; Jacques, 1992; Lishman, 1987; Norman, 1991). Individuals may, for example, be able to find their way around their own house but become disorientated when staying in the unfamiliar territory of a hospital or relative's home.

The relationship between disorientation and memory loss is a complex one but deterioration with recall does seem to exacerbate disorientation (Rabins, 1990). Once firmly established, the disintegration of intellect proceeds fairly quickly; the demented person ceases to be able either to explain or to understand concepts previously readily grasped and shared (Burns and Levy, 1992; Lishman, 1987). Fortunately, most individuals with SDAT have little insight into their condition (Royal College of Physicians, 1981) but for those who briefly experience insight, fear, frustration and anger frequently result (Gilleard, 1984; Jacques, 1992; Schwab et al, 1985).

Episodes of confusion and delirium, occurring particularly at night and which affect sleep patterns, are also reported (Armstrong-Esther and Hawkins, 1982; Clapin-French, 1986; Holden, 1991; Jacques, 1992; Lindesay, 1989; Lishman, 1987). Delusions, including persecution, occur although this is not universal and may be related to previous personality problems (Lishman, 1987).

Emotions become labile with tears, laughter, shouting and anger being easily provoked (Jacques, 1992; Lishman, 1987; Mace et al, 1985; Rabins, 1990). In the initial stages of the disease anxiety, agitation and depression may occur, partly, it is believed, in response to the recognition of cognitive deterioration (Burns and Levy, 1992; Jacques, 1992; Lishman, 1987).

In the South East London sample 17% experienced hallucinations and 20% reported delusions (Burns and Levy, 1992). In addition 24% were considered clinically depressed by psychiatrists while relatives of patients rated a much higher incidence of 43%. Depressive symptoms, as rated by patients' relatives, correlated with the identification of smaller third and lateral ventricles than normal on CT scan. This finding is of particular note in that it indicates an accuracy of perception by relatives of change in mood in the person to whom they are close and who suffers from dementia. Morrison (1983) found that relatives could assess behaviour changes accurately in people with dementia. This more recent study reinforces the issue with CT evidence of changes in pathology relating to such observed behaviour.

As the disease progresses emotions become blunted, although occasional outbursts of emotion, including irritability and anger, may occur at any stage of the disease process, particularly when there is a change in routine or environment. Burns and Levy (1992) found that 20% of the subjects in their survey had aggressive outbursts, which were most frequent in hospital patients. Restlessness, agitation and wandering may also present (Burns and Levy, 1992; Rabins, 1990); cognitive impairment and hyperactivity have been found to be key factors relating to whether or not SDAT sufferers wander (Dawson and Reid, 1987).

Physical changes in people suffering from SDAT become increasingly marked as the disease progresses. The individual's appearance changes, he reduces in stature, loses weight and his walking becomes slow and uncoordinated, all of which are associated with general physical deterioration (Lishman, 1987). Incontinence of both urine and faeces may occur, due to loss of sphincter control. In the final stages of SDAT some patients experience difficulty in eating (Lishman, 1987). SDAT may also affect a person's ability both to understand what is being said and to verbalise meaningfully, which in turn can lead to behavioural problems (Rabins, 1990). Severe physical deterioration is often delayed until the dementia has reached a very advanced stage, at which point individuals can become completely physically dependent, unable to meet daily activities of living without considerable assistance (Jacques, 1992; Lishman, 1987; Mace et al, 1985; Murphy, 1986; Norman, 1991).

The overall course of SDAT is usually steady and smoothly progressive with death usually occurring between five and seven years after the appearance of the disease; precise estimates are difficult to obtain because many cases are not seen in hospital (Lishman, 1987). The South East London study demonstrated that in a community orientated cohort only a third of patients died within three years of identification (Burns and Levy, 1992). A further longitudinal study would give more comprehensive data concerning survival. The cause of death is often due to inter-current infection although in many instances, owing to a gradual period of general decline, it is difficult to identify an exact cause (Lishman, 1987).

The progression of SDAT has been described as consisting of three phases (Lishman, 1987). The first, often lasting for two or three years, is characterised by failing memory, difficulty in undertaking the tasks of everyday life and spatial disorientation. At this stage, it is rare to find psychotic features or severe disturbances in mood, although agitation and restlessness have been reported. The second stage brings more rapid progress of intellectual and personality deterioration. The third and final stage consists of profound "apathetic dementia" (Lishman, 1987, p378) and in time the patient becomes bedridden, frequently doubly incontinent, and bodily wasting occurs (Jacques, 1992). In addition, serious neurological disability may sometimes develop, with individuals suffering severe rigidity, forced grasping and groping may be seen, along with sucking reflexes (Burns and Levy, 1992; Jacques, 1992; Lishman, 1987). In a small percentage of cases, grand mal fits occur (Burns and Levy, 1992; Lishman, 1987).

Remission and fluctuations are not characteristic of SDAT. Most people suffering from this form of dementia display a progressive course of cognitive and physical decline due to changing cerebral pathology (Burns and Levy, 1992; Gilleard, 1984; Lishman, 1987; Mace et al, 1985; Murphy, 1986; Rabins, 1990).

2.4 Multi-Infarct dementia and differences between MID and SDAT

Approximately 20% of people who present with clinical signs of dementia are found at post-mortem examination to have had multiple areas of cerebral infarction, the characteristic pathology of multi-infarct dementia (Katona, 1989). This form of dementia is related to arteriosclerosis:

> "The majority of infarcts in MID patients are thrombotic in origin, secondary to atheroma formation in the cerebral arteries and arterioles." (Katona, 1989, p.86)

The onset of MID is frequently acute due to "a frank cerebral vascular accident" (Lishman, 1987). An acute onset and subsequent "abrupt step like progressions" (Lishman, 1987, p.387) which are attributable to small infarcts are characteristic of the disease (Hachinski, 1987; Katona, 1989).

In the early stages of MID people may suffer headaches, dizziness and syncope, visual difficulties, dysphasia and transient hemiparesis (Lishman, 1987). When the onset is gradual, emotional and personality changes may occur prior to memory and intellectual impairment (Jacques, 1992; Lishman, 1987).

Depending on the severity and focus of each infarct patients may experience clouding of consciousness, ranging from confusion to coma and physical disability ranging from loss of feeling in a particular part of a limb to hemiparesis, dysphasia and cognitive impairment (Katona, 1989; Lishman, 1987; Norman, 1991). Initially symptoms may be transient followed by a period of gradual improvement but in time fluctuation becomes less frequent and permanent neurological damage results (Jacques, 1992; Lishman, 1987). Some patients experience long periods of stability between infarctions but more commonly multiple infarcts occur over a period of three to five years leading to serious disability and, eventually, death (Katona, 1989).

The progression of MID and SDAT differ although the symptoms experienced are frequently similar, particularly for individuals who experience several small infarcts over many years (Katona, 1989; Lishman, 1987; Norman, 1991). The clinical picture can be further complicated because individuals sometimes suffer from both MID and SDAT (Royal College of Physicians, 1981).

The person with MID may, because of the patchy nature of their psychological deficits (due to the nature of cerebral damage relating to infarcts), preserve their basic personality until late in the disease and retain their intellectual capacity for longer than people with SDAT (Katona, 1989; Lishman, 1987). In these instances people retain insight which, understandably, frequently leads to depression and anxiety (Hachinski, 1987; Katona, 1989; Lishman, 1987). Emotional outbursts are more common in people with MID than SDAT (Jacques, 1992; Lishman, 1987). These may take the form of crying, laughing or anger. The physical symptoms experienced by people with MID include those associated with arteriosclerosis. These include hypertension, leading in some instances to dizziness, cerebro-vascular accidents and associated physical deterioration, and neurological symptoms such as changes in gait or dysphasia (Katona, 1989; Lishman, 1987; Royal College of Physicians, 1981).

Up to 30% of people with MID may suffer epileptic fits, and syncope is common. Clouding of consciousness, especially in the evening, is a symptom displayed almost exclusively by people with MID (Lishman, 1987; Royal College of Physicians, 1981). This may lead to "florid nocturnal delirium" (Lishman, 1987, p.387) which presents as severe confusion and in some instances distress and aggression as the evening progresses.

A scoring system based on the specific signs and symptoms of MID has been developed to aid diagnosis (Hachinski, 1987). Although a useful indicator, its application with very elderly people in whom either form of dementia is advanced must be questioned, because there will be considerable overlap in the signs and symptoms displayed, whether individuals have SDAT or MID (Lishman, 1987). The most accurate methods of differentiate diagnosis involve using techniques of computed tomography (CT) and nuclear magnetic resonance imaging, which reveal clear images of the brain, combined with consideration of the symptoms with which individual patients present (Katona, 1989). In practice many patients do not have access to such sophisticated equipment, resulting in diagnosis being reached entirely on the patient's presenting history (Lishman, 1987).

Accurate diagnosis of the type of dementia from which a person suffers will indicate whether or not medical intervention is likely to influence the course (Lishman, 1987; Philpot and Burns, 1989; Royal College of Physicians, 1981). Anti-hypertensive therapy may slow down the progression of MID, although in most instances when the disease is present in older people, sufferers will continue to deteriorate over time (Royal College of Physicians, 1981). There is no known drug treatment for SDAT although intensive research into the area is being conducted (de Belleroche, 1989). In most instances treatment for elderly people with both SDAT and MID relies on non-invasive therapy including behavioural approaches aimed at reducing and alleviating symptoms as far as possible (Henderson, 1990; Norman, 1991; Rabins, 1990).

2.5 Dementia and CREST

More people are living longer in Britain, with a particular increase in the very old, those aged 80 and over (OPCS, 1991). The prevalence of dementia in Britain rises with age, increasing to 10% in those aged between 80 and 90 years (Copeland et al, 1987; Kay et al, 1964). The symptoms of both SDAT and MID result in sufferers initially requiring assistance with activities of living, and eventually to be enabled to die peacefully with dignity, both of which are traditionally nursing roles (Henderson, 1960). CREST was initially conceived as a nursing service which would assist patients in the way described and support their informal carers. Despite defining the need from a patient's perspective, it was not possible to initiate a new nursing service without establishing its relevance in the light of social policy concerning health and social care. It would have been ethically unacceptable to offer a new service to patients and their carers without first establishing that, should it be successful in terms of patient and carer outcome, its long term future would be potentially secure in terms of funding.

The next sections of this chapter review literature pertaining to social policy and related issues which have affected and are predicted to affect how health and social care for people with dementia may be structured on a national scale over the next decade.

2.6 Social policy: the national perspective

In Britain, Government policy aims to enable frail elderly people to remain in their own homes, rather than to admit them to long stay hospital beds or residential homes (DHSS, 1978, 1981a, 1981b; Department of Health, 1989a). The original reasons for this policy stemmed from a humanistic philosophy. A succession of investigations into large psychiatric hospitals had revealed inadequate standards of care (Baker, 1974; Butler and Vaile, 1984; DHSS 1972, 1981a; Health Advisory Service, 1982; RCN and British Geriatrics Society, 1975). These problems were particularly disturbing in psychogeriatric wards where chronic underfunding and understaffing were commonplace, with patients' basic human rights in terms of dignity and choice being ignored (Baker, 1974, 1978; Robb, 1967). Similar issues were identified in some residential homes (Hughes and Wilkin, 1987; Norman, 1980). The need to rethink the provision of care for elderly mentally ill people became urgent not only for reasons of poor standards of care but also because of the predicted increase in the population of elderly people in Great Britain and the increasing expectations of clients and their families (DHSS, 1978; Henderson, 1990; Henwood, 1992; Lindesay, 1989).

Reports published by both Labour (DHSS, 1975) and successive Conservative (DHSS, 1978) governments concluded that the best way forward would be to increase community based provision, a view endorsed by the Royal Commission on the NHS (1979).

While appearing straightforward, in practice, the closure of hospitals and redistribution of resources to provide community care is a complex issue (Social Services Committee, 1985). It is indisputable that a reduction of NHS hospital bed provision for long-stay elderly people has occurred since 1974 (DHSS, 1981a; Department of Health, 1989a, 1991b; Henwood, 1990, 1992b). During the period 1974-84 hospital beds in the mental health and mental handicap hospitals were reduced by 37,000 (DHSS, 1986b). In 1978 nearly half of all NHS beds including those in psychiatric hospitals were occupied by elderly people (DHSS, 1986b). Thus the reduction in mental hospital facilities reduced availability to elderly people with dementia who had traditionally occupied the majority of long stay psychogeriatric beds (Jolley and Arie, 1978). Over the ten year period 1978 to 1988 a reduction of 5000 in-patient geriatric beds occurred (Henwood, 1990).

The most recent Department of Health statistical reviews showed that in 1989 the NHS long term bed provision for people aged over 65 years was 12,000 in the Geriatric Medicine sector and 17,680 in the Psychiatry of Old Age Division in 1989 (Henwood, 1992b).

If "Community Care" is interpreted as a short-hand phrase "to refer to community based services which provide an alternative to residential or institutional care" (Henwood, 1990, p.18) then there should be ample evidence of a growth in community facilities to provide for elderly people with dementia.

2.7 Re-distribution of resources to community care

The need to redistribute NHS resources previously allocated to inpatient care to community care was identified as paramount, if the latter was to provide services for those people who might previously have been admitted to hospital (DHSS, 1975, 1981b; Department of Health, 1989a, 1990). This has not been achieved as successfully as might have been expected, largely owing to the administrative divide between Social Services and the National Health Service (Audit Commission, 1986; DHSS, 1988a [Griffiths Report]).

The Audit Commission (1986) criticised the slow move to community care and identified the barriers which were resulting in less effective care than was desirable for people living in their own homes. These included fragmentation and confusion of responsibilities, lack of bridging finance to prepare community based services prior to reduction in residential facilities and inadequate staff arrangements, including those for retraining of hospital staff, and insufficient recruitment to community based services.

It is reported that the speedy implementation of the community care policy has caused problems for elderly frail people, as the services necessary to support them at home have not developed sufficiently rapidly to meet demand (Davies and Challis, 1986;

Sinclair, 1990; Twigg et al, 1990). This applies equally to both social and health services. The Audit Commission (1986) found that the provision of two domiciliary services, home helps and meals-on-wheels, had not increased with the growth in the number of people over 75 years living in their own homes who required these services.

District and auxiliary nurses cater mainly for the nursing needs of elderly people in the community, yet provision varies widely (Dunnell and Dobbs, 1982). In this group the ratio of nursing staff to elderly people ranged from 213 per 100,000 in one district to 608 per 100,000 in the most well provided district. Kratz (1982) reported that over the decade 1967-77, the number of district nurses increased by 37% while there was an almost fourfold increase in the number of clients attended. Of the district nurses sampled by Dunnell and Dobbs (1982), 63% reported that elderly people were in need of more care from nurses than could be delivered. They particularly wished to give more time to elderly people living alone and those who were terminally ill. More recent figures showed that district nurses treated an increasing number of people over the age of 65 years in the period 1982-87 without a corresponding increase in the workforce (Department of Health, 1991b). There is no evidence, therefore, that a reduction in NHS beds for the elderly has resulted in increased district nursing provision on a national scale.

Although the number of community psychiatric nurses (CPNs) employed between 1985 and 1990 increasedthere was actually a decrease in the percentage of CPNs working specifically with elderly people (White, 1990). In 1985, 505 CPNs reported working with elderly people (64% of the CPN workforce at that time) while in 1990 the figure was 796 (59% of CPNs) (White, 1990). It is difficult to interpret these figures precisely because many CPNs carry generic case loads; therefore, the total rise in the number of CPNs employed has probably increased provision to elderly people and their carers.

There was a 42% increase in the provision of residential care over the decade 1976-86, which is estimated to be at least 50% more than could have been expected to meet demographic demand (Henwood, 1990). The increase in private sector provision was in the region of 250% against an increase of only 3% for local authority provision (Table 2.1).

	1976	1986	% INCREASE
Local Authority Residences	99,000	101,700	+2.7%
Private (Res. and Nursing)	21,300	77,600	+264%
Voluntary Sector	23,800	25,000	+5.5%
Total	**144,100**	**203,400**	**+42%**

Table 2.1 - Number of residential and nursing home places available 1976 and 1986 for people over 65 years of age
(DHSS, 1988c)

The Audit Commission (1986) partly attributes the growth in private sector provision to the perverse effects of social security payments to individuals in private residential care, which occurred in an unplanned fashion. In effect it was possible for both health and social services to place elderly people in private residential and nursing homes and then ensure that individuals in financial need received their fees through the Income Support System. Unlike both the health and social services the amount of finance available through this system was not cash limited. It is estimated that at

1988-89 prices government expenditure rose from under £50 million per year in 1981-82 to more than £900 million in the year 1988-89 in income support grants for elderly people living in these privately run facilities (Department of Health, 1989a; HM Treasury, 1986). There is no evidence to suggest that the elderly people who have entered private residential care in the last decade are those most cognitively and physically disabled. Indeed, the level of income support grant (£130 for Residential and £180 for Nursing Homes at 1988 prices) militates against these facilities being able to provide sufficiently high staff:client ratios to meet the needs of people with severe dementia (Lindesay, 1989). The vast expenditure on this form of care has caused considerable political disquiet, resulting in recommendations to ensure that people who are admitted to these facilities in future actually require residential care (Department of Health, 1989a). The report stresses the difference between residential and community care, stating that:

> "The successful implementation of community care policy depends crucially on the availability of and easy access to adequate and appropriate services in the community." (Department of Health, 1989a, p.3)

2.8 Humanistic and economic reasoning

Although the policy of community care was originally based on humanistic reasoning, some believe the policy is now favoured for economic reasons, with informal carers increasingly providing community care with no financial recompense (EOC, 1982a,b; Henwood, 1992a). The strategy paper "Caring for People" (Department of Health, 1989a) reinforced economic reasoning, clearly stating that the cost of publicly funded increases in residential care were unacceptable. Current social policy seems to favour the argument that community care "has become synonymous with family care" with statutory services (health and social) providing a back-up to family care rather than occupying the front line themselves (Sinclair, 1990, p.51).

Community care has been adopted partly for economic reasons, although it is recognised that such care might appear cost-effective only because the level of provision is inadequate and/or because no financial value is calculated for the contribution of informal carers (DHSS, 1981b; EOC, 1982a; Glendinning, 1992; Henwood, 1992a). Increased research into the role of carers following an Equal Opportunities Commission report in 1982 has provided a more thorough understanding of their lives and a greater appreciation of the problems that carers face (Henwood, 1992a). It is partly because of increased knowledge about carers that made them a legitimate target for health and social care. "Caring for People" states that "a key responsibility of statutory service providers should be to do all they can to assist and support carers" (Department of Health, 1989a, para. 2.3). The paper also emphasises that "assessments of client need" should include considering the wishes and requirements of both carer and people cared for, the continued ability of the carer to provide care and that services should be flexible enough to enable clients and carers to exercise choice (Department of Health, 1989a, para. 3.2.6).

2.9 Social policy and CREST

Social policy in Britain dictates that the majority of elderly people suffering from dementia are likely to be cared for at home with appropriate community orientated health and social service support (Department of Health, 1989a; Henwood, 1990; Henwood and Wicks, 1984). Public resources are being diverted away from traditional residential and in-patient care to more flexible forms of community based provision (Audit Commission, 1986; Department of Health, 1989a). In the light of this policy, the development of CREST is deemed appropriate because "Caring for People" (Department of Health, 1989a) clearly states that patients and those who care for them at home should be able to choose the most appropriate services to meet their specific requirements from a range of provisions. Therefore, the long term future of CREST should ensure the service's "fitness for purpose" rather than being forced to close as a result of social policy.

CHAPTER 3

BEING AN INFORMAL CARER OF AN ELDERLY PERSON WITH DEMENTIA

3.1 Introduction

The aims of this study involved not only the development of a high quality individualised night nursing service for elderly people with dementia, but also one which supported informal caregivers by working with them in partnership. In order to develop a relevant partnership between nurses and informal carers it was necessary to understand the nature, motivation for and effects of protracted caregiving. The literature concerning caring for a relative or very close friend with dementia is reviewed and the theoretical issues which were considered when developing CREST are highlighted.

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Two research reports which provide insight into caring for elderly confused people in Britain are reviewed extensively, because their findings were considered particularly pertinent when planning CREST. The first, conducted by Green (1988) with the 1985 General Household Survey, provided reliable national data on the scope and extent of informal care. An informal carer was defined as:

> "A person looking after or providing some sort of regular service for sick, handicapped or elderly person living in their own or another household." (Green, 1988, p.3)

This definition rests on the instrumental notion that looking after a person involves regular service. The second study used a qualitative approach to examine the effect of community services on 150 informal carers of elderly confused people (Levin et al, 1989).

The Levin study was conducted in two outer London boroughs and part of a county covered by a similarly sized health authority.

3.2 Clarifying the concept of caregiving

It is assumed in much of the literature that there is a universal understanding of the concept of "informal caregiving" (Green, 1988; Griffiths, 1988; Henwood, 1990), yet in fact there are many different interpretations and understandings of the term (Biegel et al, 1991; Dunlop, 1986; Finch and Groves, 1983; Graham, 1983; Twigg et al, 1990). The very nature of "informal caregiving" revolves around human relationships; therefore explanation of its structure and processes will be tentative rather than scientifically based (Nolan et al, 1990). It is not possible to state 'universal truths' concerning caregiving, as the people involved in any caring relationship are individuals with unique personal characteristics which influence their behaviour, feelings and cognitive processes (Rogers, 1980). The difficulty of trying to understand caregiving has led many to take an instrumentalist approach to interpretation (Twigg, 1986). This has resulted in a plethora of research which attempts to explain what is involved in providing informal care by examining two themes; the scope and extent of informal care and the demands made of carers (Nolan et alt, 1990; Twigg, 1986). Although this kind of research assists in understanding informal caregiving, it fails to provide qualitative insights.

Checkland (1982) argues that what he terms a "soft system" approach to theory analysis is useful in developing an understanding of complex organisations which involve human behaviour. Analysis of informal caregiving using a "soft system" approach would involve examining as many factors and interpersonal relationships within each "caregiving unit" as possible. Such an approach appears daunting because each carer, the person for whom they care, and any other people or services which impinge on that dyadic relationship would formulate a "unit". Despite the difficulties involved with this type of analysis, an increasing number of projects which used qualitative approaches, including in-depth examinations of individual caregiving units, have been published (Adams, 1987, 1989; Biegel et al, 1991; Bowers, 1987; Carlson and Robertson, 1990; Dawson, 1987; Graham, 1983; Green et al, 1982; Levin et al, 1989; Phillips and Rempusheski, 1986; Savishinsky, 1990; Silverman and Huelsman, 1990).

Each study conducted in this way attempted to explain one or more elements of the processes involved within caregiving, while some also attempted to interpret the motivations for and results of caring. Although each study used a different methodological approach, all included grounded theory (Glaser and Strauss, 1967) or an ethnographic design (Field and Morse, 1985) in an attempt to grasp the experiences and practices of carers and those for whom they provided support (Kulman et al, 1991). Most of these studies were based on small samples because of the time consuming nature of this kind of research (Field and Morse, 1985). Although acknowledging the difficulty of generalising from small studies based on different definitions of caregiving, and where samples have reflected certain sections of the community, the results provided more detailed insight into the real nature of caregiving than more quantitative studies (Kulman et al, 1991).

3.3 The numbers, role and responsibilities of primary caregivers

The General Household Survey (GHS) of 1985 identified six million carers in Great Britain, 3.5 million women and 2.5 million men (Green, 1988). This figure has been disputed by Parker (1992) who argued that the calculations were made on data collected by asking people whether they provided "self-care" or assistance with "household activities" to another person. This may have led to several respondents replying in the affirmative while the care they delivered may not have been to someone with a disability. The figures illustrated, however, that more men reported caring than was previously acknowledged (Green, 1988; Parker, 1992) and that over 700,000 people reported giving both personal and physical care to another. Most individuals who suffer moderate or severe dementia will fall into the category of requiring both personal and physical care. When planning CREST it was important to try to predict who the carers of expected patients might be in order to tailor the service appropriately. People who require both physical and personal care are most frequently cared for by spouses living in the same household (Green, 1988). When no spouse is available care usually falls to a filial member, most commonly daughters or daughters-in-law (Lewis and Meredith, 1988; Qureshi and Walker, 1989), a notion which is reinforced by the GHS data (Green, 1988). The role and responsibilities of a carer are closely related to the capacity for self-care of the person for whom they provide support (Biegel et al, 1991; Jacques, 1992; Levin et al, 1989; Mace et al, 1985). There are two traditional notions of role, one in which a role is articulated by the action of others and the second when a role is a set of expectations held by others within which the "actor" finds himself encompassed (Bannister and Fransella, 1980).

These concepts assist in understanding how an individual may take on the role of carer without necessarily considering all that it may entail. Initially, people may take the role voluntarily because of a change in the behaviour of the person for whom they commence caring (Finch and Groves, 1983; Mace et al, 1985). For example, a husband may take on a limited caring role for his forgetful wife by ensuring that she turns off electrical appliances, accompanying her when she goes shopping to prevent her from getting lost and generally covering up her forgetfulness (Bowers, 1987; Levin et al, 1989). Over time family, friends and professionals may perceive him as the "primary carer" of his wife, and ascribe additional duties to him as a result of their expectations of his role (Dawson, 1987; Oliver, 1983). Thus carers may find themselves faced with a more comprehensive set of tasks and responsibilities in looking after their relative than they had originally foreseen (Biegel et al, 1991; EOC, 1982; Levin et al, 1989; Pitkeithley, 1989; Qureshi and Walker, 1989). Some carers take on the "expected role" willingly while others may do so only reluctantly (Biegel et al, 1991; EOC, 1982; Finch and Groves, 1983; Hirshfield, 1978, 1983; Kohner, 1988; Levin et al, 1989; Oliver, 1983; Twigg et al, 1990).

Caring is time consuming and demanding. Forty-five per cent of carers looking after someone in the same household devote at least 50 hours a week to caring with 53% providing personal care (Green, 1988). When the person being cared for is both elderly and confused, caring is likely to involve more than minimal practical assistance in order to ensure safety (Biegel et al, 1991; Bowers, 1987; Levin et al, 1989; Mace et al, 1985; Murphy, 1986; Twigg and

Atkin, 1990). A recent survey found that carers supporting an individual with Alzheimer's disease reported having an average of only 13.5 hours rest a week from the caring role (Alzheimer's Disease Society, 1991).

It has been suggested that caring involves two elements: concern for an individual, and the actual work of looking after other people when they cannot look after themselves (Graham, 1983; Parker, 1981). Looking after someone involves two types of work: practical assistance which involves helping another person with non-intimate tasks including shopping, gardening and housework is often undertaken by neighbours and friends as well as relatives. Personal care is less likely to be undertaken by non-kin carers because of the intimate nature of some of the tasks (Finch and Groves, 1983; Henwood, 1990; Levin et al, 1989; Mace et al, 1985). Thus unless there is an extended kin network, carers involved with personal care are more likely to undertake this kind of care without any help from friends or neighbours (Dawson, 1987; Levin et al, 1989; Twigg, 1986). Parker (1981) used the term "tending" to describe personal care such as feeding, washing, lifting, protecting and comforting another human being. He notes that washing may include the intensely intimate tasks of cleaning up individuals who are incontinent of both urine and faeces. Tending forms a major part of caregiver roles when they are supporting people suffering from severe dementia because of the nature of the disease. Tending is not only time consuming and intensely personal it also can be extremely demanding physically. Lifting an individual on and off a commode or toilet, taking their weight as they walk up and down stairs, or moving less mobile people regularly in bed to prevent pressure sores can be physically exhausting (Kohner, 1988; Levin et al, 1989; Mace et al, 1985; Twigg et al, 1990).

Carers are frequently responsible for this level of physical activity for 24 hours a day, sometimes getting up in the night several times to turn their relative and/or assist their toileting (Alzheimer's Disease Society, 1991; Levin et al, 1989; Mace et al, 1985). When either urinary or faecal incontinence or both occur the carer will be faced with changing relatives' clothes, bedclothes and/or mopping up floors, chairs and mattresses, all time consuming, heavy physical tasks. Carers may be faced at 2.00 a.m. with the unenviable choice of either leaving their relative to sleep, knowing that the outcome will be a wet bed to change in the morning, and to suffer guilt for having allowed this indignity, or to get up and take them to the toilet while being aware that this may be a fruitless task which results in neither person being able return to sleep. Incontinence, particularly faecal incontinence, causes carers high levels of stress because of the unpleasant and intimate nature of clearing up faeces and washing people who have soiled themselves (Kohner, 1988; Levin et al, 1989; Mace et al, 1985; Pitkeithley, 1989; Sanford, 1975). One study suggests that faecal incontinence precipitates carers into seeking hospital care for people they support who are suffering from dementia (Sanford, 1975).

The comforting role within tending envisaged by Parker (1981) is especially demanding of carers when the person they support has severe memory loss. There is a constant need to reassure people who cannot remember what the time is, or where they are or, even more distressingly, who is the person caring for them (usually a close relative) (Burns and Levy, 1992; Levin et al, 1989; Lishman, 1987). Thus, in addition to the carers' practical and personal tending responsibilities, there are those relating to changes in the behaviour of the person for whom they provide support (Burns and Levy, 1992; Jacques, 1992; Levin et al, 1989; Mace et al, 1985; Nolan et al, 1990).

Concurrent with increased physical deterioration most people suffering from dementia will display deteriorated patterns of behaviour (Burns and Levy, 1992; Jacques, 1992; Katona, 1989; Lishman, 1987). Most carers of people with dementia are expected to cope with a wide range of behavioural problems. Those that are reported to cause the greatest difficulty and distress to carers are highlighted in this section. Levin et al (1989) and Dawson (1987) found that carers experienced greater difficulty with behavioural problems than with problems of personal care.

The issues of night time wandering, confusion, restlessness and enuresis have been identified as particularly difficult issues for carers to deal with, because of their own chronic loss of sleep resulting from such behaviour (Beigel et al, 1991; Lindesay, 1989; Mace et al, 1985; Sainsbury and Grad de Alarcon, 1970; Twigg, 1986; Watkins, 1987a). In order to help carers identify "trying" behaviours Levin et al (1989) used a predetermined list. Carers reported finding all behaviours listed as potentially difficult to deal with and identified an additional category concerning abuse and aggression. All the following were reported to cause carers concern:

> "Clinging, repetition, restlessness, mistaking the supporter for someone else, destructiveness, losing or hiding things, embarrassing odd or unusual acts, abuse or aggression and crying." (Levin et al, 1989, p.65)

Most of the behaviours reported as difficult to deal with by Levin's sample of carers have been similarly identified in other studies, particularly changes in emotional behaviour (Adams, 1987; Carlson and Robertson, 1990; EOC, 1982; Green et al, 1982; Hirschfield, 1983; Mace et al, 1985). Although the predetermined list was clearly a useful prompt for the interview, the omission of certain types of behaviour must be questioned (Levin et al, 1989). Other behaviours including sexual disinhibitions and masturbation, have also been identified as difficult for carers to deal with, partly because of their taboo nature (Jacques, 1992; Mace et al, 1985). It is argued that supporters would have been unlikely to volunteer such behaviours as particularly difficult problems for them without prompting, not only because of the social taboo associated with discussing such acts, but also as a protection the people for whom they cared.

Carers are expected to protect those for whom they care from harm. This expectation comes from both carers themselves, who regard protection as a central responsibility within their role (Alzheimer's Disease Society, 1991; Green, 1988; Henwood and Wicks, 1984; Levin et al, 1989), and from external parties including family members, neighbours and professionals (Biegel et al, 1991; Boss, 1988; Oliver, 1983; Qureshi and Walker, 1989).

As individuals with dementia cognitively decline there is an increasing danger that they will come to personal harm in a variety of ways relating to their decline. For instance, they may wander off and become lost or forget to turn off electrical appliances. This kind of risk is at a peak when an individual is still physically mobile (Jacques, 1992; Lishman, 1987; Mace et al, 1985). Over time sufferers may, owing to physical deterioration, become immobile, at which point these problems cease. However, when they do occur carers are faced with difficult choices. Do they allow the person with dementia those human rights associated with independence, at the risk of personal harm, and have they the right to make such decisions? These issues have been extensively debated in terms of professional caregivers' responsibilities with cognitively disabled elderly people (Norman, 1980) but are far less well rehearsed with regard to informal caregiver relationships (Jacques, 1992).

Caring in a family unit is a private affair, and an outsider can never know all that goes on (Boss, 1988; Biegel et al, 1991; Qureshi and Walker, 1989; Ungerson, 1987). Yet it seems reasonable to assume that carers adopt strategies to protect the person for whom they care from harm in a way which the carer finds most acceptable. This may involve a 24 hour watch (Mace et al, 1985), turning what may have been a loving, supporting relationship between two individuals into one that more closely resembles that of prison warder and prisoner at home. One carer, describing how he dealt with this problem, said "Locks and bolts everywhere, we've come round to that." (Levin et al, 1989, p.47); indicating not only the extent of control he took over from his mother, but also his despair in taking this action. One study which used a grounded theory approach to investigate the role of adult caregivers providing care for ageing parents identified five overlapping responsibilities (Bowers, 1987). Although the parents were not necessarily suffering from dementia, all had been diagnosed as having a chronic, life- threatening illness, and so the findings are relevant to the experience of adult caregivers providing care to elderly parents with dementia. Much of the caregiving work involved was described as "invisible" and was deliberately aimed at preserving the self-esteem of people suffering from illness.

The five responsibilities were termed anticipatory, preventative, supervisory, instrumental and protective care (Bowers, 1987). It was argued that protective care was the central focus of the model and involved preserving the self-esteem of the sick person. Carers reported this kind of care to be the most difficult and the most important to achieve. Although protective care occurred throughout the caring relationship, albeit at different levels of intensity, the other four categories were to some extent sequential. Anticipatory care involved identifying what assistance would be necessary in the future and making plans to ensure that this would be available. Preventative care consisted of monitoring the parent's behaviour and illness; for example, ensuring that diet and medication regimes were adhered to, and observing for deterioration relating to illness. Supervisory care was regarded as a progression from preventative care but with carers still trying to minimise the amount of assistance delivered in order to preserve self-esteem. Thus preventative and supervisory care were associated with protective care. Instrumental care involved carrying out personal care for parents and was perceived as the least stressful, presumably because anticipatory work had prepared both parties for this end. No reference is made by Bowers (1987) to the difficulties of coping with resistant confused parents who displayed difficult behaviour; this may be because many of the subjects had malignant diseases that are not associated with these problems. Nevertheless, this work goes a long way towards explaining the complexities of looking after an elderly ill parent and illustrates that the responsibilities go far beyond "caring for" (Green, 1988) and include an element of "caring about" (Graham, 1983) in terms of preserving self-esteem (Bowers, 1987). This study also indicates the complex nature of responsibility involved in caring, including cognitive appraisal in order to enhance the instrumental care delivered.

The instrumental definition of caring identified by Green (1988) failed to acknowledge the deep rooted "caring about" experienced by most caregivers concerning the person for whom they care (Adams, 1987; Bowers, 1987; Graham, 1983; Hirschfield, 1978; Levin et al, 1989; Oliver, 1983; Parker, 1981; Ungerson, 1983). Indeed, Parker (1981) suggests that tending is likely to lead to close relationships which involve affection and obligation which make it difficult to abandon. Others would argue that affection and obligation are precursors to the caregiving role (Hirschfield, 1978, 1983; Levin et al, 1989; Oliver, 1983). In reality the two are likely to ebb and flow, changing in intensity according to circumstance, as in most family relationships (Boss, 1988).

Caregiving has been identified as having at least four dimensions: duration, intensity, complexity and prognosis (Parker, 1981). Caregivers of individuals with dementia are likely to conduct care for between one and seven years, in line with the prognosis of the disease (Lishman, 1987), during which time carers will require special skills to deal with both physical and behavioural problems experienced by the sufferer (complexity). The role is almost invariably intense, involving giving 24-hour assistance not only with tending but also with protecting from harm and preserving self-esteem. The difficulties of providing each piece of care cannot be isolated and solved independently; rather, carers have to select the most appropriate forms of coping with the tasks and responsibilities involved within the role in a holistic manner. The difficulties of caring for close relatives or friends who display changes in their mental as well as physical state is summarised in a pharmacy health care leaflet produced by the Alzheimer's Disease Society (undated), as follows:

> "Caring for someone with dementia is a difficult and demanding task. Someone you have loved gradually disintegrates as a person before your eyes, and your relationship with them changes completely. There are no simple answers to the problems you will face, no simple rules to follow that will work every time - if there were you would have found them already." (p.1)

This description goes beyond the instrumental, recognising not only the changing nature of the relationship between caregiver and cared for attributable to the dementia, but also the fact that there is no effective prescriptive answer to ensure a good caring process.

3.4 Motivation for undertaking an informal caregiving role

The reasons for undertaking this role vary for each caregiver although recent theories and research indicate some common factors concerning the issues involved (Beigel et al, 1991; Eagles et al, 1987; Levin et al, 1989, Qureshi and Walker, 1989; Savishinsky, 1990). There are two schools of thought regarding the motives for helping others; one assumes that helping serves an egotistic or self-serving motive, the other centres on altruism and empathy (Bannister and Fransella, 1980).

The "egotist" theory regards people as motivated by either the anticipation of reward for helping or punishment for refusing to do so. Rewards may include gaining social approval by complying with social norms; seeing oneself as a good person (Bandura, 1977); or avoiding guilt (Brody, 1985). Biegel et al (1991) suggest that caring for a relative and enabling them to stay at home, thus avoiding institutionalisation, can be interpreted in at least three ways: to avoid censure, seeing oneself as good, and complying with social norms.

Guilt and indebtedness are two egotistical motives frequently cited as reasons for becoming a carer (Brody, 1985; Finch and Mason, 1990). Greenberg (1980) suggests that indebtedness has motivational properties which produce feelings of discomfort and arousal in proportion to the level of indebtedness. Thus the stronger the indebtedness, the greater the attempts by people to reduce their sense of obligation. A sense of indebtedness is clearly a motivating factor for many who take on the caring role (Biegel et al, 1991; Brody, 1985). This theory may explain, at least in part, why kin who are more distant than spouses or children take on the role. For example, a niece or daughter-in-law may care for an aunt or mother-in-law because the older person was especially kind to them in the past (Levin et al, 1989).

"Guilt" as a motivational force for caring is less well explained. Brody (1985) suggests that it may be related to the carers' beliefs that they behaved badly towards the person for whom they care at an earlier stage of their relationship and wish to atone, or make things right through caregiving. A powerful motivating factor for many caregivers is the anticipated feeling of "guilt" if their relative has to be admitted to institutional care (Kohner, 1988; Levin et al, 1989).

Filial obligations and duty are frequently cited as reasons for taking on the caring role (Biegel et al, 1991; Dawson, 1987; EOC, 1982; Finch and Groves, 1983; Finch and Mason, 1990; Jacques, 1992; Levin et al, 1989; Oliver, 1983; Zarit et al, 1987). Dawson (1987) reported several carers who cited marriage vows as the reason for caring for their spouse. Children caring for elderly parents with dementia reported that it is a "duty" for families to support their own (Dawson, 1987; Levin et al, 1989; Pitkeathley, 1989), a sentiment which reflects current British social policy. Seventy two per cent of the carers sampled by Levin et al (1989) reported that their reasons for caring involved kinship and duty, the honouring of promises, and lack of acceptable alternative options. These responses suggested that in a high percentage of "caregiving units" carers took on their role as a result of obligation and willingness to care which arose from the ties of marriage and descent (Levin et al, 1989). Barusch (1988, 1991) believes that filial obligation results from the fact that in many families individuals lives are "intertwined around each other" making separation extremely difficult even if desired.

The "intertwining" referred to by Barusch (1988, 1991) may account for a tentative theory which suggested that a factor for many in the taking and continuing of the caring role was a fear of anticipated loneliness if the role was terminated (Levin et al, 1989; Oliver, 1983; Savishinski, 1992; Silverman and Huelsman, 1990). Many caregivers lived in a dyadic relationship with the person for whom they cared for over 20 years. Although the majority were spouses, a proportion were children who had never left the parental home (Atkin, 1992; Green, 1988; Levin et al, 1989). Peplaw and Perlman (1982) suggest that loneliness involves a cognitive appraisal process and occurs when individuals compare their social relationships against standards and find themselves deficient. The factors which influence the standards against which comparisons are made may include past social experiences, the social activities of peers and fantasy. Caregivers may believe that they are less lonely than retired peers because they are busy and, in the case of some women, continuing in what they regard as "normal work" for women in the home (Graham, 1983; Ungerson, 1983). An alternative interpretation suggested that loneliness occurred as a result of emotional isolation and the lack of an intimate relationship, together with social isolation and small social networks (Ribeiro, 1989). As a result of conducting a caring role for a protracted length of time some carers reported very limited social networks (Atkin, 1992; Dawson, 1987; Green, 1988; Levin et al, 1989), which suggested that loneliness would be a severe problem for carers if people for whom they cared were admitted to residential care or died. It is concluded that affection and reciprocity between carer and cared for may be a powerful protection against a lonely old age for some carers, combining both egotistic and altruistic drives (Biegel et al, 1991; Levin et al, 1989).

Several authors believe that there are sociological reasons for undertaking the caregiving role in terms of responding to the social norms of society (Biegel et al, 1991; EOC, 1982a; Fennell et al, 1988). Current social policy results in families acting as firstline caregivers with the responsibilities of statutory services being to support those families (Department of Health, 1989a; Qureshi and Walker, 1989). The majority of families look after disabled relations willingly (Qureshi and Walker, 1989). Similarly, both Dawson (1987) and Levin et al (1989) found that most carers of elderly people with dementia wished to continue caring and merely desired extra support from statutory services to do so rather that to abdicate the role. Generally it is agreed that families have altruistic reasons for taking care of their own, but conflict may exist when "the family bond is confused with what is expected of health and social services" (Dartington, 1986, p.72).

Altruistic motivations for accepting the caregiving role undoubtedly exist (Dawson, 1987; EOC, 1982a; Levin et al, 1989). Many people help others because they empathise with those for whom they care and wish to improve their circumstances. The empathic response is considered an emotion which evokes motivation, the magnitude of which is related to the degree of emotion experienced (Biegel et al, 1991). Although there may be benefits to the helper of providing help, the prime motivating force is to benefit the dependent. Biegel et al (1991) suggest that although it has not been demonstrated empirically, the ability to empathise may be based on such variables as kinship, similarity, prior interaction, attachment, or a combination of these, all of which are relevant to family caregiving situations. It has been argued that people can only feel "cared for" rather than "serviced by" friends and relations because the personal nature of the care they receive is by "virtue of pre-established social relationships" rather than bureaucratic provision (Qureshi and Walker, 1989, p.146).

Caring has been described as a "labour of love" (Finch and Groves, 1983) which involves the emotions associated with love, including caring for and about others. Levin et al (1989) found that love was the prime motivating factor for 25% of the 150 carers of elderly confused people they sampled; it was most continuously cited by spouse carers. Caring demands labour and love and the nature of the demands are shaped by the social relationships within the caregiving unit and the norms of wider society (Finch and Groves, 1983).

Caregiving transcends the accepted separateness of public and private lives, home and work, leisure and labour, which may result in a failure to understand the complex experiences and motivations involved in the role (Biegel et al, 1991; Finch and Groves, 1983). Although caring relationships may be started and sustained by a productive balance of reciprocity, affect and trust (Qureshi and Walker, 1989), when people have dementia there may come a time when, due to cognitive decline, they can no longer contribute to relationships at an emotional level. At this stage a carer's motivation may become increasingly egotistic (Biegel et al, 1991). Oliver (1983) indicates one way in which carers may reward themselves and use caregiving as an egotistic motivating force for continuing to care by quoting a carer who said:

> 'When carers become completely convinced that no one else can do their work, they are awarding themselves the status which society denies them.' (Oliver, 1983, p.76)

She continued pointing out that love and affection as motivating factors can and do co-exist with egotistic drives.

Graham (1983) tried to explain what she believed are two elements of caring; the "feeling" and the "active work" components. She described the emotional root of the caregiving role which involves intimacy and affection, emotions being interpreted as self-motivators. The mutuality between caregivers and dependents was well described by Hirschfield (1983), who likened it to "love for another". Repricocity seems to be an important feature in this interpretation, when the caregiver gains affection from the dependant, as well as vice versa. Many carers report satisfaction from helping the person they care for and are thankful they are able to help. Witnessing the comfort and contentment of their relative is sufficient reward for them to continue (Levin et al, 1989). The "active work" of caring, Graham (1983) suggests, can provide a "work identity" which may be related to a caregiver's self esteem. She suggested that this may be one reason for women accepting the caring role, especially when paid work is difficult to get. It is recognised that in British society, individuals acknowledge and accept their responsiblities to family members who are disabled. The reasons for this acceptance are complex and include internal stimuli such as feelings of love and guilt, reciprocity between carer and cared for, and external pressures such as society's expectations at both a macro (political) and micro (family) level (Qureshi and Walker, 1989). These are powerful pressures which encourage individuals (particularly women) to commence and sustain the role, sometimes inappropriately, for both caregiver and recipient. The costs of being involved in an appropriate caregiver/recipient relationship may at times be unacceptable.

3.5 Benefits and costs of caring

Social policy dictates that an increasing amount of care will be given by families at a cost to all family members, especially the primary caregivers (Henwood, 1992a), the majority of whom are women (EOC, 1982a; Ungerson, 1983) although male members of families are increasingly taking on the role (Green, 1982; Henwood, 1992a; Levin et al, 1989; Parker, 1992).

The social exchange theory suggests that individuals only stay in relationships if the benefits outweigh the costs (Homans, 1961). This theory can be applied to caregiver/receiver relationships in that, as already demonstrated, some caregivers do receive tremendous reward, whether from friends and relatives, the receivers of care or from personal satisfaction relating to their role. Caregiving may be particularly rewarding when conducted for a short time and when receivers get better (Atkin, 1992; Ungerson, 1990). It is much more complex when caring for people suffering from dementia, when caregiving is likely to be protracted and receivers become increasingly dependent (Levin et al, 1989; Mace et al, 1985).

The last decade has seen an increasing interest in and research into the costs of caregiving (Twigg, 1992). For the purpose of this study literature concerning caregiving with elderly mentally frail people is reviewed because of its relevance to the anticipated partnerships between caregivers and nurses in CREST. More generic studies are examined to illuminate issues as necessary. The costs of caregiving can be summarised into four categories, economic, physical, psychological and social; in most instances two or more factors are interlinked. For example, reduced income leads to caregivers being unable to afford their previous social behaviours such as visiting friends or going out for a drink (Adams, 1987, 1989; Biegel et al, 1991; Gilhooley, 1984; Gilleard et al, 1984; Green et al, 1982; Hirschfield, 1983; Kuhlman et al, 1991; Levin et al, 1989; Mace et al, 1985; Pratt et al, 1987; Rabins et al, 1982; Twigg et al, 1990; Zarit et al, 1985).

Carers frequently feel tied down, suffer from lack of personal free time and develop feelings of resentment, hopelessness and guilt as a direct consequence of delivering home care to those suffering from dementia (Hirschfield, 1983; Levin et al, 1989). Similar findings were reported as early as 1970 by Sainsbury and Grad de

Alarcon. They identified that caregiving caused a severe effect on family dynamics, together with emotional disturbance in carers, a third of whom, when interviewed, reported suffering headaches and depression. Carers of people who had dementia stated that leisure and social activities were severely restricted and domestic routines upset (Sainsbury and Grad de Alarçon, 1970).

Further studies in the 1970s and early 1980s indicated that intolerable strain was placed on caregivers, which related to the physical and behavioural disabilities presented by their relatives who suffered dementia (Bergmann et al, 1978; Gilhooly, 1984; Green et al, 1982; Sanford, 1975). Green et al (1982) developed two rating scales, one to assess the degree of behaviour and mood disturbance shown by people with dementia, the other designed to measure the amount of stress and disruption of caregivers' lifestyles resulting from having to care for an elderly relative with dementia. Thirty eight main caregivers of day hospital patients were then asked to complete the two sub-scales. The results demonstrated that personal distress in caregivers was closely related to patients' passive withdrawn behaviour rather than to their level of cognitive functioning. Patients' behavioural manifestations of dementia not only caused caregivers personal distress, but also resulted in carers experiencing negative feelings towards their relatives with dementia (Green et al, 1982). Neither cognitive decline nor inability to conduct activities of living correlated with caregivers' experience of burden (Green et al, 1982). The patient assessment tool developed by Green et al (1982) did not include incontinence, a behaviour reported by others to cause caregivers distress, particularly faecal incontinence (Levin et al, 1983; Sanford, 1975). Gilleard et al (1984) and Levin et al (1989) in more recent studies also found that caregivers identified their demented relatives' personality and behavioural difficulties as particularly distressing.

The General Health Questionnaire (GHQ) was used by Eagles et al (1987) to identify the extent of psychological wellbeing among 79 co-resident supporters of elderly people, half of whom were caring for individuals with dementia. Eagles et al (1987) found that caregivers of people with dementia had no increased psychiatric morbidity on the GHQ when compared with supporters of non-demented relatives. Levin et al (1989) found a direct association between caregivers' psychological health problems, as measured using the GHQ, and the severity of problems associated with dementia suffered by the person for whom they cared. The difference in the results of the two studies may be attributable to the way in which the projects were conducted. Levin et al (1989) specifically investigated the relationship between care receiver behaviour and caregiver GHQ score, while Eagles et al (1987) compared two different groups of caregivers' GHQ score without linking this to specific receiver behaviour. Another factor may be the different populations sampled. Eagles et al (1987) suggest that their Aberdeen sample may be biased since the community is, by tradition, cohesive, stoical and uncomplaining. The sample of Levin et al (1989) was larger and undertaken with a more varied population than that of Eagles, and the findings confirm previous work more closely (Gilleard et al, 1984; Green et al, 1982; Zarit et al, 1985).

Many caregivers suffer both physical and psychological problems related to supporting an elderly person with dementia at home (Adams, 1987; Eagles et al, 1987; Green et al, 1982; Henwood and Wicks, 1984; Levin et al, 1989; Rabins et al, 1982; Sanford, 1975). Physical problems have been reported to include headaches, obesity and cardiovascular disease associated with stress (Hirschfield, 1983; Levin et al, 1989). The General Household Survey of carers (Green, 1988) identified that nine-tenths of all supporters reported having at least one persistent or recurring health problem. Elderly caregivers were twice as likely to have disabilities which limited their caregiving activities than younger ones. In the Levin et al (1989) sample, nearly two-fifths of caregivers reported having recurring physical health problems, the commonest being arthritis or rheumatism which afflicted nearly half of all the caregivers interviewed. In addition 40% reported recurring backache or lumbago. These results may be related to the heavy physical tasks involved with caregiving, including lifting people with dementia. A minority of caregivers were fit and active, however. To demonstrate this one person, a 78 year old male caregiver, spontaneously touched his toes for the interviewer. Conversely, a 69 year old caregiver who was interviewed had a caliper on one leg, a surgical shoe on the other and was suffering from a broken bone fractured when her husband fell on her foot (Levin et al, 1989, p.21).

The economic costs to caregivers of supporting an elderly person with dementia at home may range from the loss of paid employment and the corresponding reduction in pension rights to the increased costs of running a household, which requires extra heating and/or the provision of special diets to the person with dementia (Glendinning, 1992; Henwood and Wicks, 1984; Levin et al, 1989). Social security benefits may enhance the income of individual caregivers and the person with dementia may, depending on age, be entitled to attendance allowance. However, it is extremely rare for the totality of benefit entitlements to any household to exceed the potential income of caregivers if they gained paid employment outside the home (Glendinning, 1992). A greater degree of impoverishment is experienced in households where caregivers live alone with an elderly person who is dependent than where there is a third party, either in paid employment or who is entitled to state benefits (Glendinning, 1992; Henwood and Wicks, 1984). These findings suggest that carers who give up paid employment to care for someone with dementia do so at great personal economic cost, not only at the time of caring, but also in the longer term with regard to potential pension income. The caregivers who most frequently fall into this category are those adult filial carers who support an elderly parent with dementia, since spouse caregivers have often reached pensionable age prior to commencing the role (Glendinning, 1982; Levin et al, 1989).

The extent of social isolation of caregivers was identified in a study by Levin et al (1989), which showed that one in six caregivers who lived alone with their relative/friend lacked any regular weekly contact with another adult, relation or friend; only 4% received regular help with the personal care of the person with dementia. Caregivers also reported feeling sad and bereft at having no one with whom to share their intimate confidences, a role often previously undertaken by the spouse or parent for whom they were now caring. Older carers in Britain report being more socially isolated than their younger counterparts (Green, 1988) partly because they are provided with less practical assistance from social services (Parker, 1992). Individuals who are co-resident with an elderly person for whom they provide care report spending up to 50 hours a week caring (Henwood and Wicks, 1984). Twenty three per cent of carers aged over 65 years reported that they coped single-handedly with elderly frail relatives, a figure which increases to 42% of co-resident carers (Henwood and Wicks, 1984). Caregivers are often unable to leave their homes to meet family and friends because they need constantly to supervise their relatives who have dementia (Henwood and Wicks, 1984; Levin et al, 1989). This has resulted in some carers reporting that they have not experienced 24 hours continuous respite from caregiving since they took on the role (Adams, 1989; Green, 1985; Levin et al, 1989).

There is clear evidence to suggest that although relatives and friends may initially help caregivers, as time goes on the burden frequently falls on the primary person giving care, and social isolation can become severe (Levin et al, 1989). Most caregivers believe that their other relatives and friends should provide them with more social contact by visiting and taking a turn in caring (Levin et al, 1989; Qureshi and Walker, 1989). Even in households which contain three generations the caregiver and dependent person can become isolated (Bergmann et al, 1984; Qureshi and Walker, 1989). It can, for example, be very difficult for a teenager to bring friends home into a house where a grandparent is incontinent, displays volatile emotions and is extremely forgetful and confused (Watkins, 1987a).

The costs of caregiving have been demonstrated to be closely associated with the symptoms of dementia displayed by those people supported by the caregivers. Because of the nature of dementia, sufferers decline physically and mentally over a period of months or years resulting in changes within the caregiver/receiver relationship.

3.6 Caregiver stress

Carers who provide support for a relative or friend with dementia may take on the role because there is mutuality between them. However, once a person with dementia becomes incontinent, confused and fails to recognise their carer, the reciprocal benefits to the caregiver may all but disappear (Alzheimer's Disease Society, 1991; Qureshi and Walker, 1989). Lack of reciprocity is often a key factor in caregivers beginning to feel stressed beyond their ability to cope. The effect this may have on family dynamics often leads to carers feeling the dependent person has become a burden, and in the long term they may become exhausted (Biegel et al, 1991; Henwood and Wicks, 1984; Levin et al, 1989; Mace et al, 1985; Qureshi and Walker, 1989).

The stimulus based model of stress implies that the strain experienced by a person is related to the extent of burden placed upon that individual. Although this is a fairly simplistic interpretation, it is clearly appropriate when the stimulus is great.

The Crichton Visual Analogue Scale was developed to measure two dimensions of dependence in elderly people who had dementia (Morrison, 1983). The first dimension concerns ability to conduct activities of living, and the second dimension concerns behavioural problems associated with dementia (Morrison, 1983). Two studies identified a positive correlation between caregivers' perceived inability to cope with relatives suffering from dementia and the degree of dependence of those for whom care was provided (Morrison, 1983; Watkins, 1987a). This might suggest that carers' anxiety influences their assessment of patients' behaviour. However, because community nurses' ratings of patients correlated with carers' ratings of the same patients, it is likely to be the patients' behaviour which influences carer anxiety and diminishes their ability to cope (Morrison, 1983).

Lazarus (1976) stated that perceived threat is the central characteristic of stressful situations, and in particular, threat to a person's most important values and goals. This more dynamic interpretation is helpful when considering the stress experienced by carers looking after an elderly person suffering from dementia. Changes in relationships between caregivers and receivers are reported as stressful by carers and a very high percentage of carers report ill-health in addition to stress. Caregivers' stress may be said to arise where there is an imbalance between the perceived demands of their caring roles and their own perception of their ability to meet those demands. This interpretation fits with the transactional model of stress (Cox, 1978). This model suggests that the important balance or imbalance is not between actual demand and actual capability, but between perceived demand and perceived capability. In other words, it is important to understand that it is a person's cognitive appraisal of the potential situation and his related ability to cope that results in a situation being seen as stressful or otherwise.

Initially, stress involves initially an emotional experience which results in both a physiological and psychological response. The person can then respond to this stress either by coping or by becoming increasingly stressed. Coping is best considered as a form of problem solving, in which the stakes are a person's wellbeing. Lazarus (1976) suggested that coping can involve direct action, enabling the person involved either to change the situation or to avoid the stressful situation. Once a person begins to feel helpless and completely unable to master a situation, the threat becomes severe, and stress may in some circumstances become irreversible in terms of the damage done to the individual from a physical, psychological or social perspective. The chronic exhaustion experienced by some carers suggests that carers remain in the caregiving role for longer than their ability to cope. For example, one carer reports:

> "Caring has made me a physical and mental wreck, totally unable to relax and without a clue how to even think of myself." (Pitkeathly, 1989)

The fact that carers do not leave the caring role as readily as may be expected is probably closely related to the concept of the family and their responsibilities to that unit. The idea of family stress has recently been developed, and has been defined as a "disturbance in the steady state of the family, arising from the interaction of a number of factors" (Boss, 1988). Boss suggests that when families are in a situation where family stress is occurring, it can be difficult for the members to recognise that it is taking place (Boss, 1978, p.38). Until the family, or in the case of a caregiving unit, the caregiver, recognises that they are in a situation that is extremely stressful, it is difficult for an individual to take any kind of coping action to change their situation. Even when carers or other family members recognise the extent of stress experienced by supporting an elderly person at home they do not necessarily seek residential care for the ill person. This may be because the carer still feels affection for the other person and the nature of service has become ingrained (Graham, 1983). In addition, institutional care may not be perceived as care because at the beginning of the caregiver/dependant relationship, the dependent person has been able to express that they felt cared for, and the carer has felt special in the way they deliver care (Biegel et al, 1991: Qureshi and Walker, 1989). Therefore, the special nature of informal care is perceived by the carer as much better than formal care.

Carers' perceptions of stress are mediated by factors such as denial; failing to admit the extent of deterioration; and suffering experienced by the person for whom they care (Adams, 1989). Denial can act as a "protector" from stress and increase a carer's ability to cope. The family stress model suggests that it is the perceptions of family members, coupled with their resources both in financial and personal terms, and the events to which they are subjected, that result in family stress occurring. The slow deterioration of someone suffering from dementia, can, therefore, be a major family stressor. The extent to which a family succumbs to stress will be dependent on that family's resources in terms of previous learning, finance and individual members' intrinsic strengths (Adams, 1989). An understanding of stress, and in particular family stress, goes some way to illustrating the reasons for carers' reported stress, and ultimately their ill-health.

When carers experience severe stress this can result in poor quality caregiving (Alzheimer's Disease Society, 1991; Bennett, 1990; Levin et al, 1989; Tomlin, 1989). This may involve passive abuse, failing to talk with the ill person, denying them access to family and friends and leaving them for long periods of time in clothes soaked with urine following incontinence.

Active abuse also can occur. This may take the form of mental cruelty, shouting or goading and physical abuse including shaking, pinching and slapping the confused person. Abuse of an elderly confused person by a caregiver is closely related to caregiver burnout and represents a complete breakdown in the relationship between the two. The theoretical understanding as to why abuse occurs in some families and not others is limited, although it relates to the resources within the family (Adams, 1991; Boss, 1988).

Qureshi and Walker (1989) tried to establish how, even in very difficult caregiving relationships, carers continued to go on, and found that this was related to two factors: the quality of the relationship between caregiver and dependent person in the past, and the extent to which children had felt emotionally close to the parents whom they were supporting. Two thirds of the children supporting a parent said that even though there was no reciprocity at the time of interview, there had been considerable help in the past, and the fact that it was now one sided was irrelevant. Caregivers in these situations made statements such as:

> "When I needed her she would come at the drop of a hat."
>
> "As I say, she struggled to bring me up, I can never do enough."

Very few of these children actually mentioned love, but they did point out duty and obligation. Both Qureshi and Walker's work (1989) and Levin et al (1989) demonstrated that the most difficult thing caregivers found was when adverse personality changes occurred in the dependant and that this often provided a crisis point in the relationship between caregiver and dependant. Clearly, relationships change between carers and dependant over the period of the caregiving relationship. The extent of reported stress and ill health among caregivers would lead to the submission that many carers remain in the supporting role even when the costs to them exceed the benefits. The reasons for so doing are complex; family dynamics and the nature of stress and exhaustion are but two possible factors which prevent carers from "giving this role up". Isaacs et al (1972) found that 23% of elderly people admitted into acute hospital beds were taken in due to caregivers' real need rather than the dependant's deterioration. Isaacs et al argues that this is an indicator that carers press on without sufficient outside support until a crisis occurs.

There is little doubt that the caregiving relationship can only be produced and sustained by a productive balance of reciprocity, affect and trust (Qureshi and Walker, 1989). Social exchange is different from purely economic exchange, and depends on issues such as gratitude and affection. Therefore, once the dependant is unable to appreciate the personal attention given by the caregiver and to return affection, carers often experience stress. The challenge to nursing staff seems to be to provide flexible services that enable carers to cope: so that the perceived demand upon carers does not exceed their perceived ability to cope. There is clear evidence to suggest that such services do not yet exist. The latest report from the Alzheimer's Disease Society (1991), which canvassed carers on their use of respite care services, illustrated that most carers believed there was "not enough care available to them to support them in their role". The paper described respite care as any care "which allows the usual carer free time or a real break from caring". Such care should, they suggest, "not only enhance the life of the carer, the carer's family and the sufferer; it should also allow the carer to cope for longer periods".

3.7 Summary

The literature reviewed in this chapter indicates that caregiving for an elderly person suffering from dementia is time consuming and both physically and emotionally demanding. Caregivers experience personal distress as a result of the behaviours displayed by their relatives who have dementia and, for some, the distress becomes sufficiently severe to result in related psychological and physical health problems. The reasons for caregivers taking on and continuing their role vary. Where reciprocity, mutuality and trust between caregiver and receiver are prime motivations the mental decline of the person with dementia may lead the caregiver to reappraise the benefits of caring. Alternatively, some caregivers may suffer such severe stress that they become unable to recognise their own levels of exhaustion and strain and thus cannot make decisions about their own future or that of the people for whom they care.

If stress is examined as a reflection of lack of fit between the individual and the environment in which they find themselves, it is easy to see why carers experience severe pressure which in time leads to strain, stress and fatigue. The challenge to health care services must be to find sufficient support mechanisms to enable carers to cope with their situations (Twigg, 1992). Coping does not necessarily mean keeping the dependent person at home, although from that person's perspective, this may well be the most appropriate intervention.

The challenge to nurses in CREST is to assist caregivers in identifying how they might best be enabled to cope, which may involve not only encouraging them to use flexible community services, but in some instances accepting residential care for their relatives.

CHAPTER 4

PATIENTS AND CAREGIVERS AS CLIENTS

4.1 Introduction

The aims of CREST were to provide optimum nursing care to patients by working collaboratively with those people who were primarily supporting them at home and to provide a respite service to those caregivers. Literature concerning the way in which community orientated services have been structured to meet similar aims is reviewed. Subsequently, the factors within those services which caregivers and clients value are discussed. A summary of the issues particularly relevant to those involved in planning CREST is then presented.

4.2 Evaluation and successful organisational structures of community based services

One third of the Social Services budget and more than 40% of the Health Service budget is spent on elderly people, yet services for elderly mentally ill people are perceived by many to be poor (Evans et al, 1986). There is an expectation that new services should clearly identify their aims and evaluate whether these are achieved both in order to demonstrate accountability and to alter services in line with the findings of evaluation (Department of Health, 1989a,b,c; Henwood, 1990; Landsberger, 1985; Smith and Cantley, 1985).

Selected literature concerning the evaluation of community based services in Britain provided to elderly people with dementia and their families forms the next section of this chapter. When innovative schemes are examined the results need to be treated with caution, because "new projects" are always popular with staff and attract a commitment and enthusiasm that can lead to unrealistic assessments of their value and importance (Lindesay, 1989). The schemes which have been selected for discussion are those which have been specifically aimed at supporting both carers and elderly people with dementia. Home is the place where most elderly people wish to remain, rather than be admitted to residential care, and in most instances this can only be achieved for individuals with severe dementia if they receive a degree of caring support from family and friends (Bergmann et al, 1983; Levin et al, 1989; Lodge, 1991).

Twigg et al (1990) identify five forms of service which support informal carers in their caring role. The first form was aimed at supporting carers and the second at assisting carers with practical tasks. The third form supported carers by providing relief from their caring roles and the fourth type involved empowering carers to obtain more from voluntary, health and social services. The final type of service which Twigg et al (1990) identified was aimed at providing a quality service to people supported by carers. The schemes reviewed in this chapter fall into all these categories. Those discussed in most detail are facilities orientated towards assisting the carer by providing quality services to the person for whom they care, and by providing relief from the caring role.

Successful services have been found to have similar operational structures including local neighbourhood links, strong and committed local champions of change, a focus on action rather than bureaucracy, multi-disciplinary approaches and partnership between services including health, social and voluntary sectors which resulted in integration (Audit Commission 1986). There has rarely been co-ordination of care between health and social services for elderly people who suffer dementia and their families, resulting in at best fragmented rather than client-centred care (Lindesay 1989).

It is essential for health and social services to clarify their roles and responsibilities for providing care to prevent replication or omission of services (Griffiths, 1988). The following factors have been found to assist joint planning:

1. Coterminous health and social services boundaries
2. Joint decision making
3. Bottom up approaches
4. Specialisation social work teams for elderly people
5. Adequate resources to prevent jealous gate keeping
6. Understanding by each service of other services' problems
7. Joint data bases regarding client groups
8. Joint monitoring and evaluation (Murphy 1988)

As new services are developed it is vital to define the aims of those services, that workers are both available and responsive to recipients' needs and able to work with other disciplines to provide comprehensive care packages (Challis and Darton, 1990; Department of Health, 1989a; Jolley and Arie, 1978). Griffiths (DHSS, 1988a) concluded that, for community care to become reality, local diversity had to be regarded as a strength, with innovation and commitment being encouraged. The values of innovative community services for elderly people and their relatives should be those of normalisation, choice and local accessibility (Audit Commission, 1986; Department of Health, 1989a; Henwood, 1990). Services for dementia sufferers and their relatives must try to meet the physical, psychological and spiritual needs of all who may be affected by the problem, including neighbours (Norman 1989). The recognition that no single standard can exist is emphasised by Norman (1989) who states that each service needs to be:

> "a living and growing organism which responds to perception of its objectives, awareness of its failures, and development in its relationship with its caring partners" (p. 193)

When receiving health or social care people with dementia should be afforded the same human rights as any other member of society and be treated in an individualistic manner (Kings Fund Centre, 1986). The same paper states that people with dementia have the right to support which does not exploit family or friends. This standard is an essential one if the human rights of both people with dementia and their carers are to be preserved.

It has been argued that at times access to some form of residential care is essential for people who have severe dementia in order to ensure adequate care and to prevent the breakdown of carer/dependant relationships (Bergmann et al, 1983; Finch and Groves, 1983; Levin et al, 1989; Norman, 1989). Thus, the value of both respite and long term residential care must be recognised and appreciated by those working in health and social services, rather than be perceived as a "last resort" when community care has failed.

4.3 Residential respite care

Residential respite care is provided for elderly mentally frail people, who are predominantly cared for at home, by both health and social service departments (Nolan, 1991; Henwood, 1992a; Jacques, 1992; Levin et al, 1989; Twigg, 1992). Clients are frequently offered a week or fortnight's stay, bookable in advance on a cyclical basis (Twigg et al, 1990). The main purpose of respite care is to relieve the carers of those who use the service (Bergmann et al, 1983; Grant , 1991; Levin et al, 1989; Twigg et al, 1990). Clients who use respite care should be provided with high quality support when receiving short term residential care offered by health and social services (Nolan, 1991; Henwood, 1992; Norman, 1980; Twigg et al, 1980).

Problems of providing respite care in Part III residential homes include some staff reporting that they perceive the permanent residents as their main priority with more ambivalent attitudes being held towards the care of temporary residents receiving short term care (Nolan, 1991). The same study identified that hospital staff had more positive attitudes towards clients receiving respite care. The reasons for these different opinions concerning the provision of respite care may have been related to hospital staff finding temporary clients a change of focus from their work with long term patients, thus enhancing morale (Nolan, 1991). Nurses are orientated towards assisting patients or clients in retaining or increasing independence in short time frames; while the focus of staff in residential homes is more frequently associated with providing supportive home care environments. These differing foci of care may be another contributing factor to Grant's (1991) results.

Recent research has identified an increased risk of morbidity and even mortality related to the use of short term residential care which may partly be associated with institutional regimes which can increase dependency (Miller, 1985; Norman, 1980; Rai et al, 1986). Another explanation advanced by Fottrell (1988) is that people with dementia who use short term care do so because their condition is deteriorating and their carers require respite from the increasing demands of supporting their relatives. He, therefore, suggests that the increase morbidity and mortality is associated with advancing disease rather than respite care.

Respite care can be a positive experience for clients. One study of hospital based respite care found that advantages to patients included enhanced sleep, reduced pain and increased mobility (Martinus and Severs, 1988). The four essential ingredients of good respite care have been described as the environment, staff, carers and users (Webster, 1988). Quality indicators in environmental terms should include privacy, routines which are flexible allowing individuals dignity, autonomy and choice and physical accommodation associated with "homes" rather than "workhouses" (Norman, 1980; Webster, 1988). When the service users are able to understand the reasons for respite care they should be consulted about where and how care is provided for them (Norman, 1980; Twigg et al, 1990; Webster, 1988), although this is not always feasible with elderly people who are suffering from severe confusion associated with dementia (Levin et al, 1989; Mace et al, 1985). Carers should be afforded counselling opportunities to reduce the guilt and stress associated with encouraging their relatives to use respite care (Nolan and Grant, 1989; Twigg et al, 1990; Webster, 1988). Finally staff need to recognise the special contribution carers have to make in working in partnership to ensure that respite care minimises potential disruption to clients by attempting to provide consistency in care delivery at home and in short term residential care (Levin et al, 1991; Nolan, 1991; Norman, 1980; Webster, 1988).

In a recent review of in-patient rota beds, carers identified the tiring and trying nature of providing care and a lack of flexible respite services (Nolan, 1991). Carers want flexible services which can be used in emergencies in addition to pre-planned regimes (Alzheimer's Disease Society, 1991; Henwood, 1992a; King's Fund Centre, 1986; Levin et al, 1989; Lodge, 1991; Nolan, 1991; Twigg et al, 1990). Carers fear being labelled as 'overdemanding' by respite services and would appreciate the opportunity to receive more information and training about how to care from staff involved in providing respite support for their relatives (Alzheimer's Disease Society, 1991; Nolan, 1991; Webster, 1988).

Although many carers perceive short term residential respite care as an essential lifeline to provide them with a break from caring, many only use the services with reluctance (King's Fund Informal Care Unit, 1987; Levin et al, 1989; Nolan, 1991; Twigg et al, 1990). This is because most carers believe that the care they are able to give their relatives is superior, because of its personal nature, to that delivered in any form of institution (Levin et al, 1989; Nolan, 1991).

Respite care can increase confusion in individuals which may be partly reduced by planning individualised care which reflects that given at home (Ineichen, 1989a; Norman, 1980; Rai et al, 1986). The potential for sharing information between carers and nurses about individual clients' needs and methods for care delivery (e.g. safe lifting) have been identified as indicators of good practice in short term respite facilities. These factors were considered when planning CREST.

4.4 Day centres and day hospitals

Day centres for people with severe dementia were considered less relevant than day hospitals where facilities to cater for the range of signs and symptoms displayed by individual sufferers were more likely to be available (Bergmann et al, 1983; Gilleard, 1984). One survey found that some clients stopped attending day centres because of the presence of confused clients (Fennel et al, 1981). The issue concerning segregation of services for elderly people with dementia from those with functional or purely physical disease is one debated at length, with opinion being divided (Bergmann et al, 1983; Brocklehurst and Tucker, 1980; Evans et al, 1986; Gilleard, 1984; Norman, 1987; Smith and Cantley, 1985). Gilleard (1984) believed that there was a reluctance in many day centres and some day hospitals to accept elderly people with dementia because of the high levels of support required by many and the adverse effect such clients may have on others.

When a carer is still in paid employment and the elderly person has only slight cognitive deterioration, day centres may provide appropriate support (Twigg et al 1990). However, as the elderly person becomes increasingly frail, carers may find the effort involved in helping them to get ready to go to the day centre disproportionate to the relief received by the carer (Norman, 1989). This is partly because day centres are often open only from 10.00 a.m. to 3.00 p.m., a time of day when some carers say they least require a break. In one study carers reported that they valued time off to go shopping and get on with household chores uninterrupted while their relatives attended a day centre (Levin et al, 1989). However, in the same sample most carers stated that because their relative/friend was at a day centre for such a short time they were unable to follow social activities (Levin et al, 1989).

Day hospitals have a more specific remit than day centres for elderly people with dementia. The Department of Health and Social Security (1972) recommended that each health district should provide 2.3 psychogeriatric day hospital places for every 1000 people over the age of 65 served in the population. In fact, few authorities did so, 1.5 places per 2000 being the average in 1982 (Gilleard, 1984). In most cases, day hospitals are associated with psychogeriatric services in a hospital unit (Gilleard, 1984). Medical assessments and treatments are conducted and qualified nurses employed (Bergmann et al, 1983; Gilleard, 1984). The provision of these services can result in quality of life improvements for patients; for example, urinary incontinence may be resolved through accurate diagnosis and treatment. Skilled nursing interventions, including behavioural techniques, reality orientation programmes, and physical and hygiene care including bathing, hair washing and chiropody may also improve patients' behaviour and physical state (Gilleard,1984; Norman, 1991).

The most comprehensive evaluation of a day hospital for elderly mentally ill people was reported by Smith and Cantley in 1985. Patients with both organic and functional illness were admitted to the service and the effects of the hospital on them and their carers assessed. Positive carer outcomes resulted from their relatives/friends attending the day hospital, including emotional support and exchange of information between carers and staff which occurred when carers attended group support meetings at the day hospital. The exchange of information concerned the patients' problems and ways of coping both physically and mentally with the challenges these problems caused carers. The interaction between carers was also reported to be supportive, in line with findings from other carer support groups (Smith and Cantley, 1985; Twigg, 1990; Hills, 1991). Few carers visited the day hospital regularly, and when they did so, visits were fleeting, with contact usually being made with a nursing auxiliary rather than with a qualified nurse or doctor, with the result that most carers played little part in decision making about their relative/friend's care and treatment. Patients were followed up one year after initial attendance, when 75% had ceased attending day hospital (Smith and Cantley, 1985). Over 60% had stopped attending because of deterioration in their condition and approximately 20% as a result of refusing to attend. Over 25% of the day hospital patients were admitted to a long stay hospital during the one year follow-up period. There was no evidence that the day hospital assisted in moving patients from in-patient beds back into their own homes. It was concluded that the day hospital did little to divert patients with dementia from the ultimate destination of in-patient care (Smith and Cantley, 1985).

In a study which compared outcomes of people who attended day hospital and day centres, those with mild to moderate dementia were found to have more favourable outcomes when they attended day centres (MacDonald et al, 1982). This finding may be related to attitudes of staff at day centres, where self-care expectations tend to prevail. Since people with dementia exhibit more severe problems, day centre and indeed day hospital staff may be increasingly selective regarding admission (Smith and Cantley, 1985; Norman, 1989). Day hospitals are perceived to have similar benefits for carers as those of day centres (Gilleard et al, 1984). In line with day centres, the restricted hours of provision in most day hospitals, termed by Murphy (1985) as "midday care" has resulted in some carers reporting relatively few personal advantages of such a service (Fennel et al, 1981; Levin et al, 1989; Watkins, 1987a). The uncertainty concerning the arrival times of ambulances, both to pick up from and return clients home has been cited as a particular problem for carers (Watkins, 1987a). Similar situations have been identified elsewhere (Smith and Cantley, 1985; Lindesay, 1989).

Smith and Cantley (1985) noted that the day hospital did not ease problems for relatives at night or when attendance was required for more days than those allocated or indeed when "the costs to the carer of patient attendance outweighed the benefits". These findings were confirmed in a study of the effects of two day hospitals on carers in inner London (Watkins, 1987a). Even when carers reported positive personal benefits from their relatives' attendance at a day hospital this did not necessarily result in the maintenance of community care (Greene and Timbury, 1979; Smith and Cantley, 1985; Watkins, 1987a). This may be because the stress and strain of maintaining a person with severe dementia at home, with only a few hours' respite while they attend day care, are too great (Bergmann et al, 1983; Fennel et al, 1981; Gilleard, 1984; Twigg et al, 1990).

4.5 Night services

A rural night sitting service which was funded by the health sector was overwhelmingly supported by principal caregivers of 60 people with dementia (Rosenvinge and Dawson, 1986). A nurse was responsible for managing the service. Sitters were easily recruited and retained, none of the patients who used the service were immobile but most had difficulty in dressing and were incontinent of urine. It was argued that, since mortality over a 20 month period was 23%, the service met the needs of a higher dependency group than those who could attend a day hospital. The scheme is reputed to have reduced the demand for long stay beds by two per annum, and thus to be cost effective. However, the way in which this calculation was made is unclear. What is clear is that this nurse led service was valued by caregivers.

The Oundle Community Care Unit was a day and night centre run by a multi-disciplinary team within a health authority with aims similar to those of CREST (Gibbins, 1986). The scheme was funded by the DHSS to develop services for people with mental illness in old age. The daytime places were available from Monday to Friday and reflected comprehensive day hospital services. Of more interest to this study were the seven night places which were available for seven nights a week. Originally clients were only able to attend the centre for one night or one day a week. An evaluation model was designed to measure the need for the service. Measurements were taken to identify the impact of the service in terms of carer relief and its effect on the treatment of psychiatric conditions of the elderly people who attended. The research team who were not involved in the setting up of the service were sceptical about the projects' aims from the start. They regarded the plans for the service as being far more orientated to the relief of carers than to the treatment of those people who were to attend.

The results illustrated that fewer people used the service than was expected and that many of the elderly people who did attend were not suffering from depression or dementia. It was argued that the service had relaxed its assessment criteria because of low occupancy (Gibbins, 1986). Another factor may be that health and social service staff did not perceive the relevance of a service to elderly people with a mental illness which restricted attendance to one session a week and thus referred only those with minimal problems.

The impact of the Oundle Community Care Unit on carers was measured by comparing their ratings on the General Health Questionnaire at two intervals, when their relative/friend first attended the unit and again after six months. The results indicated a reduction in caregivers' stress levels. These results are, however, questionable because of the 36 carers interviewed on both occasions, almost half their relatives no longer used the service. Indeed, five caregivers reported significant stress reduction because their relatives were in residential care at the time of re-assessment (Gibbins, 1986). It is reported that a small number of carers were then interviewed to elicit their perceptions of the service. Carers reported positive personal outcomes of the service, including the pleasure of being home alone at night and not having to worry about their relative/friend while they were at the Oundle Unit (Gibbins, 1986).

It was decided to measure the impact on those people who attended the Oundle Unit using the concept of clinical cure (Gibbins, 1986). This approach was considered appropriate because of the high level of trained mental health nurses employed to care for clients. Only 19 clients attended for a sufficient period of time (not specified) for the impact of their attendance to be measured (Gibbins, 1986). The results demonstrated that more individual care planning occurred for clients suffering depression than for those with dementia. The staff's work was far more orientated towards supporting carers of people who suffered from dementia and who attended the Oundle Unit than on initiating nursing care for those individuals (Gibbins, 1986). The lack of structured care for clients, particularly for those with dementia, coupled with admission procedures which attracted people with predominantly "social problems", led the researchers to conclude that the expense of staffing the service with trained nurses 24 hours a day was not warranted (Gibbins, 1986).

The Oundle report recommended that the service be radically altered to provide a centre for all elderly people in need rather than to function as a specialist unit for older people with mental illness. It further suggested that the benefits of such a service could be more cost-effectively managed by residential social workers than by nursing staff who, it was argued, were governed by strict regulations regarding the number and grades required on duty at any one time (Gibbins, 1986). The report suggested that one reason for the breakdown in the service of patients with dementia was because the original operational policy for the unit failed to indicate which treatment and services would be offered to those attending (Gibbins, 1986). Unless clear goals of a nursing service are identified by managers of that service, staff may be unable to take the lead in instigating appropriate nursing care for clients. It was essential to structure CREST so that its maximum potential in terms of client outcome could be accurately measured and evaluated.

The author visited another night hospital which was identified by Cumberledge in a community nursing review (DHSS, 1986). This service was developed after a charge nurse identified the need for night care in addition to day care for a small minority of patients who had dementia. A flexible service was developed which enabled some clients to stay for a 24 or 36 hour period once or twice a week. The operational policy clearly identified that the predominant objective of the service was to provide a respite service to carers. Unfortunately the service was never officially funded but relied on ward based night staff accepting extra clients when beds were available. It is probably the ad hoc way in which the service developed, the goodwill of practitioners that could not be sustained and the paucity of any formal data concerning the value of the service that led to its closure in 1990.

4.6 Home helps/Crossroad care attendants

The home help service is established throughout Britain and valued highly by most recipients (Audit Commission, 1986). The service relieves carers of confused elderly people by providing direct relief from housework and the opportunity for everyday exchanges, the latter being reported as particularly valuable when carers can no longer converse with their relative due to cognitive impairment (Levin et al, 1989). Although the provision of a home help was not found to be related to whether a female carer continued in the caring role, it was a factor which seemed to enable male carers to continue to provide support for an elderly person with dementia (Levin et al, 1989). Women may find the need for home help less necessary than men because they are used to performing household tasks (Levin et al, 1989) and regard these as a 'private' matter not wishing another to interfere with their routines (Ramdas, 1986).

The development of the home help role to include "assisting with personal care" as well as domestic help is now well established (Twigg et al, 1990, p38). In Dartington the home care assistant

(HCA) role has been developed to support elderly people who have differing degrees of mental frailty (Stone, 1986). In order to ensure sufficient, flexible relief for clients and their carers 30 hours of HCA time per week for each client has been found to be most appropriate. Stone (1986) recognises that if HCA support is provided at this level in conjunction with other services community support could become more expensive than the Dartington team had originally expected.

The effectiveness of other home care assistant schemes run by social service departments are currently being evaluated in many areas (Twigg et al, 1990). Preliminary results indicate that home care assistants are conducting many personal tasks, including the changing of dressings and catheter bags, traditionally considered to be the responsibility of nurses (Social Services Inspectorate, 1988). Twigg et al (1990) suggest that because of financial pressures on social service budgets, social services departments are far more likely to restrict their schemes to people living alone. Other home care assistant schemes arranged by the voluntary sector provide comprehensive care for people who look after relatives and friends in their own homes.

Crossroad care is an example of a home care scheme organised by the voluntary sector. The success of this scheme has been recognised because it gives carers temporary freedom from the caring role and relief from physical and emotional strain, while providing high quality care to disabled clients (Bristow, 1986; Lovelock, 1981). Wherever possible the Crossroads scheme tries to meet the individual requirements of the families it assists (Bristow, 1986).

Thus when a caregiver of someone with dementia clearly specifies the assistance required from an attendant, within reason this is given. The success of the scheme is illustrated by its rapid growth since the first service commenced in 1974. In 1991 more than 1.5 million care hours were provided to 15,000 people from 183 schemes (Leat, 1992). Part of this success may be because, although the service is run by volunteers, attendants are paid by social service departments at a rate tied to local authority scales and are under the direction of the caregiver rather than the person for whom they provide care.

Carers value the support of Crossroads care attendants. The factors associated with satisfaction are the regularity of help and paying the helpers, so enabling caregivers to feel they can exert a degree of control over the work that helpers conduct (Leat, 1992). Carers appreciate voluntary, unpaid sitting schemes but are sometimes reluctant to use the schemes as they do not wish to impose or accept charity (Leat, 1992). Similar attitudes were reported by Levin et al (1989) who found that older caregivers felt particularly uncomfortable accepting purely voluntary assistance.

4.7 Community care schemes

The Kent Community Care Scheme was set up to establish whether or not clients could remain in their own homes rather than be admitted to residential care if sufficient support was provided, and was evaluated by the personal Social Services Research Unit, University of Kent (Challis and Davies, 1983; Davies and Challis, 1986). Seventy four elderly people were involved in the experimental group with a corresponding control group (Challis and Davies, 1955, 1983; Davies and Challis, 1986). Clients in both groups were matched by age and level of disability, although it was not feasible to match the clients' carers. Results must, therefore, be considered in the light of the difficulties involved with comparing similar groups rather than matched controls. The scheme involved social workers (case managers) being allocated to clients with responsibility for providing individualised packages of care to each client within a set budget which could not exceed two thirds of the cost of a residential home place.

The research established the extent to which clients' well being was affected by the scheme, the way in which the service actually functioned, and the financial costs involved. The case management approach was predominantly aimed at providing services for elderly people in their own homes and, where applicable ,for their informal carers. Clients' location was identified at a three year follow up, which demonstrated that 35% of the experimental group in comparison to 12% of the control group were still at home. The majority of admissions had been to residential care, although a small percentage had been admitted to long stay hospital care. Most of the people admitted to hospitals suffered from dementia. Individuals with dementia in the experimental group who were admitted to hospital were considered to have been supported at home as long as was appropriate from the perspective of their own needs and their informal carers' ability to cope. These findings supported those of Bergmann et al (1978), who found that for people with dementia, living alone was associated with admission to residential or hospital care due to an inability to provide sufficient support to maintain them at home.

Outcomes measured suggested that the experimental group experienced a higher quality of care and a slower rate of functional deterioration than their matched controls over the period investigated (Challis and Davies, 1986). The scheme was shown to be most cost-effective for physically and mentally impaired clients who were cared for by informal carers. It was less so for equally impaired clients who lived alone. Twenty-five per cent of the clients were diagnosed as suffering from dementia. This group was both the most costly to support and most difficult to maintain at home (Challis and Davies, 1986).

The scheme also demonstrated a number of favourable outcomes for carers. Relief from stress and objective burden seemed to be the main impact on them. These findings were considered to relate to the role of the case managers in alleviating the carers' feeling of total responsibility for care (Challis and Davies, 1986). In addition, the provision of home help and other services to elderly people supported by informal carers increased and corresponded closely to the level of assistance delivered to clients living alone. The Kent case management scheme appeared to enhance the level of indirect support carers received rather than to exploit their position (Twigg et al, 1990).

Although the scheme was demonstrated to be successful in terms of client and carer outcome, several problems arose. The scheme was more expensive than originally anticipated and confusing lines of accountability were reported (Challis and Davies, 1986). Accountability became a particular issue when the case manager (who was responsible for both the assessment of the client's need and cost-containment of each client's individual package of care) indicated the amount of care that could be purchased from another professional worker. For example, district nurses believed it was their responsibility not only to plan, implement and evaluate the nursing care for any client referred to them but also to conduct an assessment of need in line with their Code of Professional Conduct (Challis and Davies, 1986; UKCC, 1983).

In the Bexley case management scheme the case management role was undertaken by informal carers who were encouraged to direct and co-ordinate support services for themselves and their dependant (Twigg et al, 1990, p64). The scheme was developed by Maitland (1983), who believed that there was a strong causal relationship between the declining cognitive function of elderly people with dementia and the subsequent breakdown in community support and admission to residential care. The majority of clients involved in the scheme suffered from dementia. When they were first referred a thorough medical, psychiatric and social assessment was conducted, and care planned and co-ordinated with the client and his family or immediate carer. The Bexley scheme relied on the prime informal carer, who either lived with, or close by, the person with dementia, being responsible for purchasing the best form of support required. The family or informal carer was encouraged to identify a suitable person to become a paid assistant. The jobs of assistants were flexibly defined, and "open to negotiation between the carer and the helper, in the light of the particular needs of the dependent person" (Twigg et al, 1990). The social workers involved acted as enablers, assisting clients and their families to obtain relevant social security benefits with which to purchase services. The evaluation of this scheme suggested that it was cost effective to social services departments. This may be because no calculation was included for the cost of social security benefits (such as dependence allowance). The extent to which this particular project was successful in keeping elderly people with cognitive disability in their own homes has not yet been fully evaluated, although initial results are encouraging (Maitland and Tutt, 1987).

The Bexley scheme's philosophy was that people should have more control over their own lives and that this was more likely to be achieved by informal carers having purchasing power than when a social worker made decisions about provision of services (Maitland, 1983). The scheme placed a significant responsibility on carers, who were expected not only to employ helpers, but also to be capable of making assessments regarding their relative's needs (Twigg et al, 1990). This scheme could be criticised for denying independent assessments to people with dementia and their informal carers. In the Kent community scheme carers reported that they appreciated sharing the responsibilty of care with case managers. This advantage was not present in the Bexley scheme. For example, if a paid helper was unable to attend to a person with dementia in Bexley, the informal carer was responsible for providing alternative support, rather than the case manager as in the Kent scheme.

Age Concern and Guy's Health District have organised a home support scheme which is predominantly the responsibility of the voluntary sector, but with health service input in terms of medical and nursing assessment as appropriate (Lindesay, 1989). The service was similar to the Kent Community Care Project with case managers employed by the voluntary sector being allocated a budget of up to the cost of a typical psychogeriatric in-patient bed with which to purchase care for individuals. The project was conducted in both an inner city district and a county town with 95 clients in the action group and 71 matched controls. The results are less clear cut than those reported by Challis and Davies (1986). Some elderly people living alone at home with dementia were kept at home longer with home support. However, whether living alone or with a carer, certain client behaviours were identified as weakening the success of home support (Lindesay, 1989). These behaviours included double incontinence, aggression to relatives, wandering, physical illness, falls, and behaviour likely to put the client and family at risk of fire through dangerous use of heaters, stoves and fires (Lindesay, 1989). It was suggested that the key to successful community support schemes was to attract early referral before carers were faced with a crisis which leads to admission to residential care, and in some cases subsequent rejection by carers (Lindesay, 1989). The Age Concern scheme found the general practitioners, health visitors and district nurses were all in a good position to refer clients to the service because of their knowledge of and access to elderly people at home. If Lindesay (1989) is correct then these health care professionals have a vital part to play in referring clients and their carers for assistance before the clients' dependence is so severe that a crisis occurs.

All the community care schemes made provision for evening and night support, if required, on condition that the total cost of purchasing support did not exceed the budget available (Challis and Davies, 1986; Lindesay, 1989; Maitland, 1983).

4.8 Nursing services

The most recent innovation in nursing care for elderly people has been the development of NHS nursing homes (Henwood, 1992b). Three NHS nursing homes were evaluated and compared with NHS hopsital wards by the Health Care Research Unit (Bond et al, 1989). All that was known about good nursing practice in long term residential care was implemented in these experimental homes (Bond et al, 1989). The outcomes of that care were positive in comparison to traditional ward care. Patients received better quality care than in wards, particularly in relation to its individualised orientation and the environment, which was domestic sized living accommodation. The NHS nursing homes had higher nursing staffing levels than the wards but were more cost-effective because of reduced overheads, including capital costs, when compared to the traditional in-patient services. Despite the positive outcomes, direct comparison of patient outcome between the groups was not possible because the ratio of qualified nursing staff to patients on some wards was much lower than in the NHS homes.

People living in the homes included individuals suffering from a variety of disabilities, including dementia and cerebro-vascular accidents. Residents who were not confused almost unanimously appreciated the home environment and the philosophy of care which encouraged self direction, choice and equity among residents (Bond et al, 1989). The positive outcomes identified demonstrate the value of nursing to elderly people in stark contrast to the outcomes of nursing at Oundle. The results of this work demonstrate that, if nursing services are adequately planned, it is possible to evaluate their effectiveness in terms of structure, process and outcome (Bloch, 1975; Bond et al, 1989).

Community nursing services for elderly people at home have traditionally been delivered by district nurses and more recently by community psychiatric nurses (Dunnell and Dobbs, 1982; White, 1990). Research concerning the activity of community nurses and the way in which these services are organised has demonstrated that elderly people do need more attention than many community nurses are able to give and that more evaluation of their work would enable more appropriate targeting of these nursing resources (Dunnell and Dobbs, 1982; Luker and Orr, 1985; Vetter et al, 1984; Wade et al, 1983; White, 1990; Wright, 1986a).

Carers of people with dementia living at home value community psyciatric nursing services which are orientated towards supporting carers and reducing their stress associated with caring (Adams, 1987, 1989; Matthews, 1987; Pollock, 1989). Similarly carers appreciate being given information about problems their relatives experience relating to dementia and how these may be minimised with appropriate interventions (Levin et al, 1989; Pollock, 1989; Watkins, 1987a). Community nurses who relieve carers by reducing their burden by conducting caring tasks or providing relief services and/or improve carers' coping capacities through information giving and training are interpreted as successful by carers in providing relevant services (Ineichen, 1989a; Levin et al, 1989; Lodge, 1991; Matthews, 1987; Pollock, 1989).

Levin et al (1989) examined the delivery of community services to elderly confused people. Nursing services were evaluated by identifying their effects on the primary caregivers of elderly people who suffered from confusion. The results demonstrated that nursing services were appreciated by caregivers, particularly when nurses assisted with practical tasks of a personal nature, including bathing and the management of incontinence. A positive relationship between caregivers' psychological health and nurses' assistance with the management of incontinence was identified (Levin et al, 1989). The project indicated the importance of nurses working with caregivers to identify which of the patients' personal tasks they most want nurses to assist with or take over on their behalf. Two cases illustrate this: a man who asked nurses to bath his elderly sister because it was too intimate a task for him to perform and a daughter carer who felt sick and stopped eating when having to dress her mother's leg ulcers. Once this task was conducted by nurses she felt much more able to cope with the other aspects of caregiving (Levin et al, 1989).

Caregivers valued the nursing service and believed it to be beneficial although no measures were taken to validate the effects of nursing on the elderly people who were confused and received nursing care. The provision of nursing was not associated with reducing the likelihood of elderly people who were confused entering residential care (Levin et al, 1989).

4.9 Issues relating to planning CREST

Section 4.3 illustrated that caregiver satisfaction was the major focus for evaluating the provision of community care services for elderly people with dementia. This must be partly because when caregiving breaks down residential care is often the only alternative care available to people with dementia. Therefore, researchers have become more interested in finding out how to support caregivers and enable to them to cope, than on assessing the benefits of services to the principal clients - the people with dementia. This interpretation of the research is being made from a nursing perspective, where the central focus of work has traditionally been the patient rather than, as for social work, entire family units. The aims of CREST were to reduce stress in caregivers while working with them in partnership to provide an optimum service to patients. It has been illustrated that nursing services could reduce caregivers' psychological distress if nurses worked in partnership with caregivers and assisted with or took over those caregiving tasks others found most difficult (Adams, 1987; Levin et al, 1989; Matthews, 1987; Pollock, 1991). Caregivers also valued nurses giving support and advice about how best to provide care (Levin et al, 1989; Pollock, 1991; Smith and Cantley, 1985) .

Any service which offers carers respite from their caring role without giving those carers a chance to talk through their feelings about using the service may falter (Twigg, 1992). This is because carers have mixed feelings, including guilt, about using respite services, which involved non-family members in caring for people whom they both care for and about. If carers are given an opportunity to explore those feelings, the initial reluctance to use seemingly appropriate services may be overcome (Twigg, 1992). This was an important factor to consider, as the success of CREST would rely on caregivers' willingness, not only to allow their relatives to attend the service briefly, but to continue attendance over a protracted period.

There were common factors within the community based services reviewed which were regarded positively by carers. These included being made aware of the purpose of the service and what it could offer (Davies and Challis, 1986; Gibbins, 1986; Smith and Cantley, 1983), caregivers having a degree of control over the amount and type of service delivered (Bristow, 1986; Leat, 1992; Levin et al, 1991; Lindesay, 1989) and the degree of flexibility of the service particularly in response to emergencies which inevitably requires 24 hour provision (Gibbins, 1986; Levin et al, 1989; Lindesay, 1989). Caregivers also reported preferring statutory services rather than unpaid volunteers (Bristow, 1986; Leat, 1992).

Elderly people who suffer from dementia are often unable to give coherent opinions about the quality and relevance of the services they receive because of confusion and cognitive decline associated with their illness. In the NHS nursing home study those residents who were able to give their opinions reported that they appreciated being cared for in a homely environment rather than in hospital wards (Bond et al, 1989). There is no reason to consider that more confused residents would think otherwise. The nursing home experiment also identified that positive patient outcomes were associated with a research based model of nursing practice which promoted residents' independence, autonomy and choice (Bond et al, 1989). The poorly managed, ill defined nursing service at Oundle failed to demonstrate positive outcomes for those elderly people who attended (Gibbins, 1986). These contrasting results indicated that CREST should have clearly defined structures and policies to maximise its potential for patients and their carers. These issues, which were considered the responsibility of management, are explored in Chapter 5.

CHAPTER 5

MANAGING NURSING PROVISION FOR PATIENTS SUFFERING FROM DEMENTIA

5.1 Introduction

A review of the literature concerning the most effective methods of managing the organisation of nursing care for patients with dementia forms the focus of this chapter. Issues including quality assurance, organisation of care, the application of theory to practice and nurses' authority are explored within the context of planning CREST. Specific nursing interventions which have been demonstrated to enhance care for people with dementia are acknowledged but not examined in detail. This is because it is argued that every qualified practitioner has a personal responsibility to deliver good quality care. The responsibility of nursing management is to set parameters within which good care can be delivered, rather than to be prescriptive about the type of clinical interventions that practising nurses should undertake. (Lancaster, 1985; NHS Management Executive, 1993a,b; Redfern and Norman, 1990; UKCC, 1992).

5.2 Quality assurance

If good quality nursing care is the right of all patients, it is necessary to identify not only what constitutes high quality care but also how care might be monitored and measured to assess and improve the quality of nursing practice (Kitson et al, 1990; Redfern and Norman, 1990; RCN, 1988). Quality is an elusive concept which has been defined in numerous ways, in some instances leading to confusion (Healy, 1988; Shaw, 1986). Two notions of quality are explored to illustrate the term as it is applied to nursing. The first notion involves considering quality as a "comparative" value; in nursing this involves measuring at least two similar services with the aim of ranking them in terms of quality (Healy, 1988; Manley, 1992). The second notion of quality is based on the concept of "fitness for purpose" (Healy, 1988). This concept of quality concerns the appropriateness and effectiveness of any service. Therefore, a nursing service could be assessed in terms of "fitness for purpose" by identifying whether it was administered to a population that actually required it and the degree of effectiveness of that service on patient outcome (Bloch, 1975; Donabedian, 1969, 1970; Healy, 1988; Manley, 1992; Shaw, 1984). Both these notions pre-suppose that indicators of quality can be isolated and measured; tasks which may be extremely complex in health services (Bloch, 1975; Donabedian, 1969; Ovretveit, 1992; Redfern and Norman, 1990).

Quality assurance models are reputed to assist people in identifying quality indicators and in monitoring and evaluating particular processes. The first stages in any quality assurance process are to identify criteria and standards which are believed to indicate quality in given situations (British Standards Institute, 1987; Lang and Clinton, 1984; Ovretveit, 1992; Peters and Waterman, 1982). The subsequent stages of these models involve measuring and monitoring the processes involved and then altering practice in the light of findings with the aim of improving the levels of quality associated with the product (British Standards Institute, 1987; Lang and Clinton, 1984; Ovretveit, 1992; St Ledger et al, 1992). This involves an industrial approach to production, where the aim is to maximise numerical output at a pre-stated quality for the minimum investment. This approach is consistent with the delivery of nursing care, as the model allows for the definition of "pre-stated quality" standards rather than maximum output in numerical terms.

The American Nurses Association (1982) developed a model of quality assurance, based on the industrial model described, which is cyclical in nature (Figure 5.1). This quality assurance cycle involves not only identifying standards and evaluating care delivered but also striving to enhance care by reflecting on and altering practice as deemed appropriate in the light of review (ANA, 1982; Manley, 1992; Watkins, 1991).

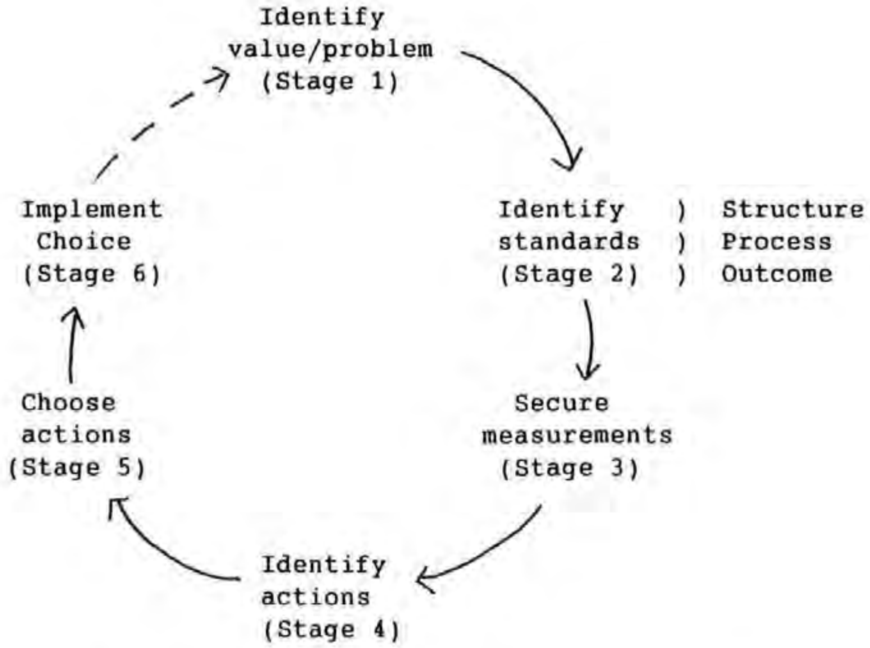


Figure 5.1 The American Nurses Association's model of quality assurance (1982)

In Britain the model has been further simplified into three stages: describing and setting objectives, measuring and monitoring and taking action (Kitson and Kendall, 1986). These three stages form the basis of the RCN's nursing quality system, entitled the Dynamic Standard Setting System (DySSSy) (Kitson et al, 1990; RCN, 1988). It has been suggested that DySSSy merely subsumed the six steps from the American Nurses Association (ANA) model into three broad stages (Manley, 1992).

The American Nurses Association (1982) and DySSSy (Kitson et al, 1990; RCN, 1988) models of quality assurance were developed for use by teams of clinical nurses. Both models suggest that a team develops its philosophy of practice based on shared values by common agreement. The ANA (1982) model adopts Bloch's (1977) approach to standard setting, which is a two staged process. First, a criterion believed to be an indicator of quality is identified. The second stage involves defining the standard which is the desired or achievable level of performance for the criterion against which actual performance can be compared. The DySSSy approach to standard setting is similar except that criteria are defined differently as "short statements which provide detailed and practical information on how to achieve the standard" (RCN, 1988). The majority of the literature supports Bloch's (1977) definition of a criterion being "an indicator of quality" (Donabedian, 1969; Ovretveit, 1992; Peters and Waterman, 1982; Shaw, 1986). The ANA (1982) and Kitson et al (1990) models agree that standards should be measurable and related to the accepted norm for a situation based on empirical evidence. For example, the empirical evidence on the development of pressure sores in elderly people who are bedfast may indicate that 5% of that population will suffer a breakdown in skin integrity within six months of becoming bedfast. Nurses should be aware of this kind of specific evidence relating to the client group for whom they care and thus be able to identify skin integrity as the criterion, and develop an acceptable standard for each criterion identified based on empirical evidence (ANA, 1982; Bloch, 1977; Kitson et al, 1990). In this example the standard could be defined as:

> "95% of patients over 65 who are bedfast in X ward should maintain skin integrity six months after becoming bedfast."

The critical time, in this instance six months, is important because measurements taken at inappropriate time intervals are rarely valid (Bloch, 1977).

Clinical teams decide how to secure appropriate measurements relating to each standard and the frequency with which care is sampled in their unit when using the ANA (1982) and Kitson et al (1990) approaches to quality assurance. Finally, a team interprets the results of evaluating care and implements change in their practice as they deem neccessary (ANA, 1982; Kitson et al, 1990). This kind of approach assumes autonomy within nursing teams with professional accountability, for standards being the clear responsibility of each registered nurse (ANA, 1982; Kitson et al, 1990). The United Kingdom Central Council for Nurses, Midwives and Health Visitors (1983 and 1989) expects registered nurses to accept this level of accountability but in practice most nurses are employees within bureaucratic structures where employers expect to be involved in both quality monitoring and control (Blau and Scott, 1964; St Ledger et al, 1992).

The DySSSy approach firmly acknowledges the role of nurse management in negotiating standards of practice while emphasising the fundamental value of nurse practitioners having ownership of standards (Manley, 1992; Kitson et al, 1990). The principles of the system are that practitioners should own and control standards; that standards should be achievable and patient focused; and that they should be related to particular nursing situations rather than be generic. The issue of standards being situation based is highly relevant in today's health service where, owing to cost-containment and the increasing need to share scarce resources equitably, have led to standards that can best be achieved in the circumstances, rather than ideal standards (Ovretveit, 1992; St Ledger, 1992). Negotiation between practitioners and managers is essential in these instances so that both parties can clarify objectives and work towards achieving the best ends in terms of patient care within economic and environmental constraints.

The DySSSy system (Kitson et al, 1990; RCN, 1988) is a bottom up approach which involves practitioners developing standards and then discussing these with the appropriate manager. The discussion between practitioner and managers should focus on three elements: that the standard is desirable and acceptable, that it is applicable to the specified client group, and achievable by a pre-specified date (Kitson and Kendall, 1986). Once the standard is agreed and accepted by management there is an expectation that managers will provide sufficient resources to enable clinical practitioners to implement appropriate change with the aim of meeting the standard. The DySSSy system encourages a partnership between practitioners and nursing managers while aiming to encourage multi-disciplinary standards of care: all essential components for achieving health service effectiveness over the next decade (NHS Management Executive, 1993b; Ovretveit, 1992; St Ledger, 1992).

The majority of quality assurance systems in use within nursing in England have utilised top down managerial approaches rather than bottom up practitioner led systems (Harvey, 1991). Generic tools to measure the quality of nursing care have been adopted by 60% of English health districts (Harvey, 1987). Monitor, a tool which combines concurrently auditing nursing records and observing nursing practice was reported to be the most widely used generic measure (Goldstone et al, 1983; Harvey, 1991). In addition, audit systems which monitor the quality of nursing by retrospective analysis of nursing records and patient satisfaction surveys were used (Harvey, 1991). These top down systems enabled nursing management to collect data to compare the quality of nursing services on similar units. The systems, particularly those which include analysis of individual patients' records, also provide information on the appropriateness of nursing care for those individuals (Phaneuf, 1976; Wandelt and Ager, 1974). This claim assumes that nursing care plans reflect the care given and vice-versa, a difficult concept to accept in English nursing when records are frequently scant and may bear little relation to the nursing care actually delivered (Audit Commission, 1991; Kitson, 1986; O'Niell, 1984).

The use of generic quality assessment tools in British nursing is currently being questioned, and research to test their validity and appropriateness is under way (Norman et al, 1992a,b; Redfern and Norman, 1990; Redfern, 1993; Sparrow and Robinson, 1992). The Mental Health Unit had chosen not to use a generic tool to measure quality of care, partly because of their irrelevance to mental health care. Bottom up approaches which adopted the notion of quality in terms of "fitness for purpose" by encouraging staff to develop and alter nursing services in response to client need were encouraged. Therefore, it is deemed outside the remit of this review to examine the literature on the application of top down generic approaches to the monitoring of quality in nursing in more detail. The Mental Health Unit approach to monitoring quality was more akin to the RCN model (Kitson et al, 1990) with practitioners being encouraged to develop clinical standards which were consistent with the overall goals of the unit. In the same way that clinical standards would be negotiated and agreed between practitioners and managers, there was an expectation that this process could also be conducted in a top down manner, with managers taking proposed standards for discussion and agreement to clinical staff.

5.3 The responsibility of nursing management in providing environments which promote quality practice

Managers of nursing services are charged with creating an environment which fosters employees' commitment to organisational goals (Lancaster, 1985). This may, at least in part, be achieved by managers ensuring that employees understand the goals of the organisation and know what is expected of them in terms of working practices in order to assist in the achievement of the goals. It has been argued that open communication systems, which enable clinical nurses to share their opinions within a climate of trust, are essential if excellence in practice is to be achieved (Lancaster, 1985). This notion is particularly important in closed institutions where in the past poor practices have prevailed and whistle blowers have been silenced rather than appreciated (Beardshaw, 1981; Copp, 1986; Goffman, 1961; Robb, 1967). Managers should also encourage individual responsibility among nurses and if possible should reward innovative behaviours/ideas if they wish nursing care to improve (Audit Commission, 1991; Audit Commission, 1992; Lancaster, 1985; NHS Management Executive, 1993a,b).

Peters and Waterman (1982) identified seven attributes from 43 of America's best run companies which Fain (1985) argued were directly relevant to the organisation of nursing care. These attributes included fostering a climate which encouraged others to try things and experiment in practice. The worst run companies did not try anything new because of fear of failure, yet Peters and Waterman (1982) argued that the greatest failure was to eliminate risks by maintaining the status quo. The second factor involved allowing autonomy to individuals within a system and giving them the chance to be creative. The third, which is closely related to the second, required that managers treat all workers as adults and partners, with the aim of increasing or enhancing productivity through and with those people. Managers and workers needed to be close to customers and to work collaboratively with them in order to design new products, or alter existing products to meet changing markets. This factor was particularly relevant to nursing in CREST, where one aim was to try to tailor the service to meet clients' needs. A further three attributes which contributed to success were a distinctive management philosophy which created a vision for workers to support, simple lean staff structures, and a factor which was termed a "loose-tight" managerial property. This latter factor involved management in setting out what they expected of workers, but also encouraged autonomy and a sense of freedom among workers within the defined boundaries. If nursing management could develop standards which demonstrated these attributes, it was argued, nursing practice would flourish and the quality of care improve (Fain, 1985).

Both Lancaster (1985) and Fain (1985) refer to management practices which enhance motivation of staff through open communication channels and the encouragement of individual responsibility. Managers also have a role in setting standards which influence the quality of technical care delivered, the environment in which care takes place and the availability of human resources, all of which can be indicative of the extent of quality within a service (Donabedian, 1970; Ovretveit, 1992; St Ledger, 1992).

The delineation of responsibility for standard setting between managers of nursing and clinical nurses is, to some extent, a false separation for, in reality, negotiation between the parties should occur and standards should be mutually agreed (Kitson et al, 1990; Manley, 1992). In practice, however, there are times when managers have to plan new services before appointing clinical staff, as was the case when developing CREST.

5.4 Structure, process and outcome standards

Standards of care fall into three categories: structure, process and outcome (Bloch, 1977; Donabedian, 1966; Kitson et al, 1990; Ovretveit, 1992; Smith-Marker, 1988). Structural standards define how a nursing system should operate, and should identify the equipment and human resources necessary for the system to function (Bloch, 1977; Smith-Marker, 1988). Smith-Marker (1988) identified nine elements to structural standards:

Description of the Unit
Purpose of the Unit
Overall objectives of the Unit
Administrative/organisation approach
Hours of operation
Criteria for admission and discharge
Governing policies
Staffing of the Unit
Nursing responsibilities by grade

This list is not exhaustive in that equipment and physical environment are not identified as structural issues. Yet the provision of wheelchair access, lifting hoists, showers and special baths would be essential at CREST where elderly people with dementia were to be nursed. Within existing nursing services many structural standards will be defined in relation to the environment and staffing policies which actually exist. In some instances the development of quality assurance cycles will enable nurses to question and alter structural standards in response to identified need (Benner, 1984; Lang and Clinton, 1984; Manley, 1992; RCN, 1990). When any new health care development occurs, at least in the initial stages, managers will need to develop and agree structural standards (Ovretveit, 1992; Smith and Cantley, 1985).

One way in which nurse managers could work towards achieving the attributes of successful managers in American companies could be to set clear structural standards encompassing the elements listed by Smith-Marker (1988). Structural standards should help practising nurses to understand their role clearly in terms of the organisational goals to be achieved and the policies governing working practice. If, in addition, the structural standards reflect the properties of open communication systems and encourage individual autonomy and participation with consumers, managers will have laid the initial foundations within which good clinical practice should flourish (Audit Commission, 1992; Fain, 1985; Lancaster, 1985).

Process standards involve defining the activities expected of nurses when caregiving (Bloch, 1977; Lang and Clinton, 1984; Kitson et al, 1990). These standards should be developed by nurses, and based on empirical knowledge and personal knowledge gleaned from experience in clinical practice (Benner, 1984; Kitson et al, 1990; Lang and Clinton, 1984). Although managers have a role in negotiating and accepting process standards it is suggested that clinical nurses will be far more motivated to achieve such standards if they are developed using a bottom up approach (Audit Commission, 1992; Harvey, 1991; Kitson and Kendall, 1986; Kitson et al, 1990).

Outcome standards are concerned with changes in patients' health status, together with their feelings, knowledge and satisfaction. Thus a standard referring to patient knowledge is an outcome standard (Aydelotte, 1962; Bloch, 1977). Outcome standards can also relate to patients' immediate family or significant others (Marek, 1989). For example, in CREST a nurse may wish to teach a patient's relative how to lift the patient safely or to explain the nature of memory loss in order for the carer to understand the disease process more fully. The latter example could have a specific outcome aim,

> "that Mrs X reduces her feelings of irritability with her husband when he forgets things by understanding the process of dementia and realising that Mr X is unable to control his forgetfulness."

This example demonstrates that many outcomes of care are best defined on an individual basis. An audit of nursing records, if accurate, should reveal the extent to which individual patient orientated outcome goals are achieved. The difficulties of measuring individual outcomes cannot be over emphasised, particularly in mental health nursing practice. The nurse makes a professional judgement concerning the extent of outcome achievement based on observation and feedback from the patient, their relatives and other health care staff. It is much easier to measure objectively a patient's change in temperature than to evaluate a change in a relative's feelings of irritability towards a patient who has dementia. Outcome standards can be devised in relation to patient populations as described earlier (Chapter 5, Section 5.2) where an outcome standard concerning skin integrity was defined (Bloch, 1977; Donabedian, 1966; Kitson et al, 1990). It should be kept in mind that nurses who are expert in the care of a very specific group of patients know the patient outcomes they are striving for, and are best able to measure patients' progress towards those outcomes (MacFarlane and Castledine, 1982; Zimmer and Associates, 1974). Clinical nurses, however, frequently need help from researchers, educators and managers to formulate measurements which assist them in evaluating whether nursing practice conforms to pre-determined standards and expectations (Bond, 1991; Bond et al, 1989; Kitson, 1986; Luker, 1981; Miller, 1985; Nolan and Grant, 1992; Zimmer and Associates, 1974).

5.5 Ideologies and models of nursing care

Henderson (1960) defined nursing as:

> "The unique function of the nurse is to assist the individual, sick or well, in the performance of those activities contributing to health or its recovery (or to a peaceful death) that he would perform unaided if he had the necessary strength, will or knowledge, and to do this in such a way as to help him gain independence as rapidly as possible." (p. 4)

She developed this definition by observation, practice and reflection. It contains the attributes of a nursing philosophy as defined by Bevis (1972) in that it provides "a point of view : a belief, construct or speculation about the value and nature of nursing". More recent literature on the nature of nursing emphasises an interpersonal component with relationships between patients and nurses being perceived as a central feature within nursing (Audit Commission, 1992; Benner and Wrubel, 1989; Kitson, 1987; Pearson et al, 1992; Wright, 1990). Pearson et al (1992) asserts that contemporary nursing involves perceiving recipients of care as holistic beings whose individual needs will, at least in part, be met by meaningful interaction between nurses and patients. Therapeutic nursing involves a partnership between patients and nurses, with patients being encouraged to be active participants in the nursing process (Pearson, 1988). In reality there are times when patients will be passive recipients of care, for example when unconscious following a cerebro-vascular accident (CVA). Conversely an elderly person who is severely obese and at risk of suffering a CVA due to raised blood pressure should be involved in discussing with nursing staff the most appropriate method of weight reduction to reduce the risk. Some patients may reject any such notion and choose to ignore the risk.

Both patients and their families may participate in nursing care with the level of appropriate participation depending on the type of health problem experienced and their motivations for involvement (Brearley, 1990; Ersser and Tutton, 1991). Having reviewed the literature on patient participation, Brearley (1990) concluded that active participation may help to overcome patients' reported feelings of powerlessness and dependency and begin to foster new working relationships between consumers and providers based on partnership. Levin et al (1989) found that carers of elderly people with dementia did want to work in partnership with nurses in delivering care to their relatives/friends but that individual carers found different tasks difficult to undertake. If carers are enabled to participate actively in selecting which care is undertaken by nurses and which they feel able to deliver themselves to their relatives, their feelings of powerlessness and stress may decrease.

Nursing has been defined in terms of caring (Baker, 1978; Benner and Wrubel, 1989; Kitson, 1987; Rule, 1978; Tiffany, 1979; Watson, 1979). Caring requires involvement which may cause stress and anxiety in nurses (Benner and Wrubel, 1989; Menzies, 1960). If nurses do not demonstrate a caring commitment to elderly patients, nursing becomes routine and impersonal (Kitson, 1987). In lay caring relationships there are close personal commitments between carers and receivers (Kitson, 1987). Nurses need to develop interpersonal skills if they wish to work therapeutically in caring relationships with patients (Kitson, 1987; Peplau, 1952). Leininger (1978) believes that it is difficult to achieve therapeutic nursing care without understanding the caring behaviour, values and practices of the group of patients and their significant others. An emotional dimension to nursing elderly people with dementia is essential, in Bergman's (1983) opinion, who cites the example of a nurse pacifying a distressed patient with a comforting embrace. Caring within nursing involves activities which include comforting and supporting measures (Kitson, 1987; Roper et al, 1980) but also includes an attitude that values individual people and respects their need for independence and dignity (Griffins, 1988; Norman, 1980). The way in which nurses view and respond to patients' situations is based on their attitudes; that is to say, nurses who care best for elderly people like them.

The role of nursing management in developing a philosophy for an entire nursing service has not been widely reported, although at least one mental health nursing service in London has attempted the task (Russell, 1992). The Maudsley philosophy was developed in conjunction with clinical staff and is applied to clinical nursing services in both hospital and community settings in the health authority including those where patients with dementia are nursed. The philosophy recognises the interdisciplinary framework within which nursing must work and clearly articulates the fundamental responsibilities of each nurse in the health authority, who is "to uphold professional values in promoting health, preventing illness, restoring health and alleviating suffering". A clear statement about nurses' individual accountability for their decisions is made, which corresponds with the UKCC (1992) Code of Conduct. It also makes explicit the expectation that nurses will keep themselves professionally up to date and apply relevant research based knowledge in clinical practice. The philosophy is written from a nurse's rather than a patient's perspective, indicating how nurses should act rather than how patients should be treated (Russell, 1992). In a consumer led nursing service a philosophy should reflect not only how nurses should behave but also what carers and patients can expect.

The Maudsley philosophy contains what are referred to as eleven standards (Russell, 1992). The "standards" are, in fact, very broad statements each with a corresponding criterion which are defined in terms of indicators of quality (Appendix 5.1). The RCN DySSSy (Kitson et al, 1990) model suggests that standard statements can be used to describe the broad objectives of a standard but that more detailed formulation of the structural, process and outcome standards relating to the statement should also be defined. Two positive attributes of the "Maudsley Standards" are that they are relevant to mental health nursing practice and easy to understand. Conversely, because they are such broad statements, it would be difficult to measure them in practice. They are not intended to be situation specific but rather a health authority's endorsed guide for good nursing practice. The role of nurse managers in assisting clinical nurses to achieve the "standards" is made explicit. This includes the provision of post-basic education and environments which promote good practice, such as the availability of quiet rooms for individual nurse/patient interaction, smoking and non-smoking areas and interpreters for patients when required. The Maudsley's philosophy and related standards statements can be viewed as a comprehensive package which explicitly states what the employing authority expects of nurses in terms of clinical practice standards, while being sufficiently broad to enable the development of unit or ward orientated philosophies and standards relating to specific client/patient needs (Russell, 1992). The package can at best be interpreted as an attempt by managers to articulate a vision for nursing that encourages clinical nurses to be innovative in practice within defined boundaries as proposed by Fain (1985) and, at worst, as bureaucratic statements of what many clinical nurses may perceive to be obvious.

A bottom up approach to the development of philosophies has been reported within nursing development units (Vaughan, 1992) and is advocated by Mawdsley (1991). There is evidence to suggest that philosophies which reflect the needs of specific client groups are most appropriate. Such statements should indicate what nurses expect to be achieved in addition to what patients can expect in terms of nursing care (Audit Commission, 1992; Brearley, 1990;

Mawdsley, 1991). Nursing philosophies develop, therefore, from examining nursing practice, concepts of health and disease and reflecting on the relationship of nursing to a particular client group, their families and society as a whole (Audit Commission, 1992; Benner, 1984; Bevis, 1982; Manley, 1992). Negotiation between nursing management and practitioners will be essential in the same way as described in a standard setting, to ensure that unit philosophies correspond with the goals of the organisation in which the unit is placed.

Individualised nursing care is encouraged in Britain. This involves nurses assessing each patient's particular nursing requirements, planning appropriate care and instigating and evaluating the care in terms of patient outcome (Audit Commission, 1992; NHS Management Executive, 1993a; UKCC, 1983). This procedure has commonly been termed the nursing process (MacFarlane and Castledine, 1982; Pearson and Vaughan, 1986). It has been argued that in order to operate the nursing process, nurses require a conceptual model on which to base the assessment, identification of patients' needs and the planning, implementation and evaluation of nursing care (MacFarlane and Castledine, 1982; Pearson and Vaughan, 1986; Riehl and Roy, 1980). Conceptual models of nursing represent their authors' philosophy of nursing, the way that they think about health, patients and the context of care in its broadest sense (Fawcett, 1992; Kershaw and Salvage, 1986; Rambo, 1984; Riehl and Roy, 1980; Wright, 1986b). Many models are assumed by their developers to be applicable to all nursing situations (King, 1981; Riehl and Roy, 1982; Roper, Logan and Tierney, 1980; Stevens, 1979). The development of models was originally conceived as the starting point from which to develop a theory of nursing (Meleis, 1985; Riehl and Roy, 1980; Stevens, 1979). A generic theory has not been achieved. Rather, there has been a burgeoning of competing models none of which are explanatory or predictive in power (Reed and Robbins, 1991). This has led to confusion in terms of explaining nursing to other disciplines, which is essential in a multi-disciplinary environment (Butterworth, 1988).

The function of a nursing model for nursing practice was described by Rambo in 1984:

> "In nursing practice a model gives direction for the assessment process and provides a systematic approach to patient care. It shows the nurse what to look for and how to provide nursing care. A model also stimulates scientific enquiry and research to validate nursing theories and concepts and to improve nursing practice." (p.5)

This idealistic notion has yet to be extensively tested in practice, in particular it is difficult to conceive a generic model of nursing which would explain "how" nurses should provide care. The generic nature of nursing models makes it difficult to test them in practice because of the lack of definition of their central variables and what they actually mean in practice (Reed and Robbins, 1991). If models are tested on specific populations then data should be collected from practice which can be used to determine their credibility through evaluation of nursing in terms of structure, process and outcome (Fawcett, 1992; Reed and Robbins, 1991). This would involve testing a model inductively in practice with its credibility resting on the congruence of the model to the nursing care of a particular population (Fawcett, 1992).

5.6 The relevance of the Roper, Logan and Tierney model of nursing for CREST

The Roper et al (1980) (Appendix 5.2) model had been adopted in the elderly care unit within which CREST operated. It had been selected for pragmatic reasons. The model was developed in Scotland as a result of observing and reflecting on the way in which nursing care was actually delivered, making it more applicable to practice in London than some of the esoteric models developed deductively in America (Pearson and Vaughan, 1986; Riehl and Roy, 1980). The Roper model is aligned to Henderson's (1960) definition of nursing which is internationally accepted and, perhaps most importantly, the model is easily understood (Watkins, 1987b). The focus of this review was to ascertain whether there was sufficient evidence to support the notion that the application of Roper et al's model would assist individual CREST nurses in individual patient care.

Reed and Robbins (1991) reported a descriptive study of the application of the Roper et al (1980) model in three wards for elderly people. Introduction of the model was a management decision. Their findings showed that nurses felt that the model constrained the care they delivered and that they found the associated paperwork repetitive. Reed and Robbins (1991) suggested that these problems were partly attributable to the way in which the model was introduced, nurses' lack of familiarity with it and rigid documentation systems. The researchers criticised the model for its emphasis on "performance of daily living activities", which they argued was not a central concern for the elderly people being nursed, but rather that those people required respect and recognition, issues they considered inadequately addressed within the model (Reed and Robbins, 1991, p.1). In reality, these criticisms are more likely to be associated with the manner in which the model was used rather than in the model itself, which recommends that all patients should be treated with respect and dignity (Roper et al, 1980).

Other researchers have indicated that Roper et al's (1980) model can assist nurses who care for elderly people by giving direction to their work and cohesion in care planning and delivering nursing (Pearson et al, 1992; Watkins, 1987b). Two of the studies involved single case applications with elderly people suffering from dementia. The first highlighted the issue of categorising patients' problems under a particular "activity of living" (Grant and White, 1983). Where, for example, should the problem of incontinence due to reduced mobility be identified; under mobility or elimination? This issue was also highlighted by Reed and Robbins (1992). The first case study also indicated that the model encouraged nurses to work predominantly with patients' physical rather than psychological and social needs (Grant and White, 1983). The nurse involved in the second case decided to add two categories of activity to the model: perception and memory (Watkins, 1987b). This encouraged nurses to consider these aspects when assessing and planning care. These categories directed nurses towards considering whether patients could recognise their relatives and remember recent events. If patient's problems existed in these areas, nurses were alerted to the need to identify ways for alleviating, or at least reducing, the problems defined. While Roper et al (1980) inferred that assessment of these activities can be incorporated within the category of communication, making them explicit enhanced the psychological and social aspects of care (Watkins, 1987b).

The community hospital at Burford was run by nurses for patients whose primary need was for intensive nursing. An experiment based on the Roper et at (1980) model was conducted to identify the efficacy of therapeutic nursing for elderly people who had undergone internal hip fixation. A total of 164 patients were included in the trial, with 84 randomly assigned to the Burford treatment group and 73 to the control group, who received traditional care. The experimental group were transferred to Burford from the acute hospital at the earliest convenient time. The control patients remained in conventional care, which included medical and elderly care wards. The results of the Burford experiment demonstrated:

> "That the quality of care provided by the unit was well above average and the hypothesis that nursing has a therapeutic contribution was supported by the fact that 6 months after discharge the life satisfaction of patients randomised to the Burford unit was significantly higher than that of patients randomised to the normal hospital ward." (Pearson et al, 1992, p.11).

The therapeutic effect of nursing identified in the Burford experience was related to many factors, including, it is argued the informed application of the Roper model of nursing (Pearson et al, 1992). It is extremely difficult to isolate variables within any health care setting and identify the extent to which nursing behaviours result in specific patient outcomes (Bloch, 1975; Davidson, 1977; Luker, 1981; Manley, 1992; Miller, 1978, 1985;

Phaneuf, 1966). Despite these methodological problems there is sufficient evidence from the Burford experiment and the individual case studies examined to suggest that the Roper model has assisted practitioners in organising high quality nursing care for elderly people.

Roper et al's (1980) model is less explicit about patients' relatives' roles regarding participation in care than is Orem's (1985) nursing model of self care. Orem's model explicitly states that patients' families should play an active role in assisting ill family members in their self care activities. There is, of course, no reason why such a concept should not be applied when using Roper's model. Nurses are encouraged to alter existing models of nursing through application and evaluation in practice (Fawcett, 1992; Pearson and Vaughan, 1986; Wright, 1986b).

The aim of CREST involved not only caring for elderly people with dementia but also working in partnership with carers. In addition, one of the service aims was to reduce carers' stress associated with delivering care to their relatives or friends who suffered from dementia. Thus, although Roper's model may be an appropriate framework for nursing CREST patients, a focus on reducing stress in carers was also required. Stress reduction techniques can be aimed at reducing burden and/or assisting people who are stressed to increase their coping ability (Adams, 1991; Cox, 1978). Nurses in CREST could try to reduce carers' burden by identifying the areas of care which they found most burdensome and either providing a substitute service for those care tasks or, through a problem-solving approach, construct other methods for doing so. The latter approach may involve the use of health education and providing relevant information (Adams, 1991; Matthews, 1987).

Zarit et al (1985) developed a stress-reduction approach for social work practice with families in which a member suffered from Alzheimer's disease. There were two stages to the approach, information giving and problem solving. In the first stage social workers gave information about Alzheimer's disease and the range of services available to help both the person with dementia and other family members with associated problems. The second stage involved family members and social workers working in partnership to resolve the particular problems identified within the family unit. Family members were encouraged to select solutions which they believed would be most appropriate to their circumstances (Zarit et al, 1985). The social workers empowered families by providing sufficient information to enable the family members to make informed choices. The application of this model together with the Roper model could provide a more comprehensive framework for the orientation of nursing in CREST than either model applied in isolation.

5.7 Methods of organising nursing and skill mix

The way in which nursing is organised in a ward, unit or community team will affect the required skill mix (Carr-Hill et al, 1992; NHS Management Consultancy Services, 1987; North Western Regional Health Authority and University of York, 1992; Rowden, 1989, 1992; Thomas, 1992). Three methods of organising nursing staff functional or task, team and primary nursing are considered.

Functional nursing divides nursing work into tasks, with the nurse in charge allocating work to appropriate nurses based on the level of skill required to undertake particular functions (Berry and Metcalf, 1986; Kron, 1981; North Western Regional Health Authority and University of York, 1992; Pembrey, 1975).

When team nursing is practised groups of nurses are allocated to patients for a period (Waters, 1985). It is generally agreed that each team should have a leader who is normally a qualified nurse. The team leader takes responsibility for delegating the nursing care of particular patients to members of the team (Thomas and Bond, 1990). Opinions differ with regard to the way in which the team leader may allocate work. Durbin (1981) believes that the team leader can allocate tasks to members of the nursing team while Kron (1981) insists that if nursing work is organised in this way task not team nursing is practised. The generally accepted interpretation of team nursing in Britain is that team leaders allocate work associated with the total care of patients to team members for at least an entire shift, taking into account the education and competence of each member (Thomas and Bond, 1990; Waters, 1985). The planning, documentation and reporting about care may be conducted by all team members or the team leader alone (Durbin, 1981; Waters, 1985).

Although it is difficult to conceptualise precisely the exact components which characterise team nursing, no such difficulties arise with primary nursing. A registered nurse is designated as the primary nurse for a small number of patients for the duration of their care within this method (Giovannetti, 1980; Manthey, 1970, 1980; Thomas and Bond, 1990). Each primary nurse takes responsibility for planning and evaluating all aspects of individualised nursing care (Thomas and Bond, 1990). Autonomy, authority and accountability are prerequisites for the primary nurses role (Marram, 1976; Sellick et al, 1983; Thomas and Bond, 1990).

The NHS Patient's Charter states that each patient should have a named nurse when they require nursing care (Department of Health, 1991c). The nurses' rules indicate that every registered nurse should be accountable for the assessment, planning, allocation of work associated with implementing care and evaluating care for each of the patients for whom they are responsible (UKCC, 1983). The UKCC Code of Conduct (1992) and the paper Scope for Professional Practice (1992) remind qualified nurses that they are not only responsible for the nursing they undertake but also for that which they allocate to nursing assistants, health care assistants and students of nursing. The NHS Patient's Charter (Department of Health, 1991c), the Nurses Rules Approval Order (UKCC, 1983) and the UKCC guidelines can be followed by managing nursing in a functional, team or primary nursing mode. In reality it is difficult to accept that the functional mode could operate easily within the guidelines described. The recent Audit Commission (1992) handbook for head clinical nurses recommends the practice of team or primary nursing, suggesting that these methods of organising nursing work are associated with the Government's concept of the named nurse.

5.8 Nursing organisation, skill mix and patient outcome

A positive relationship between the use of task allocation for organising nursing care and increased dependence in elderly hospitalised patients was identified by Miller in 1985. Investigations into poor nursing practice in elderly care units have consistently reported that the fragmentation of care associated with task allocation often resulted in nurses not knowing exactly who was responsible for specific sections of patient care (Committee of Inquiry Ely Hospital, 1969; Committee of Inquiry Whittingham Hospital, 1972; Robb, 1967). This, in turn, led to serious omissions in nursing care. The findings from hospital enquiries into poor nursing practice for elderly people, Miller's work and the current opinion concerning the expected autonomy of qualified nurses were considered sufficient to reject the use of task allocation for organising care in CREST.

The need to discriminate between team and primary nursing is essential if the two organisational modes are to be comparatively evaluated in practice (Thomas and Bond, 1990). Six features were identified by Thomas and Bond (1990) for the purpose of categorising the way in which nursing was organised in elderly care wards: the grouping of nurses and the time of allocation to specific patients, the allocation of nursing work, organisation of the duty rota, nurses' accountability for patient care, responsibility for writing patients' notes and liaison with medical/paramedical staff (Thomas, 1992). A multiple choice questionnaire was designed to establish the organisational method of delivering nursing care in wards designated to either acute or rehabilitative care of elderly people. Twenty one ward sisters/charge nurses responded to the questionnaire, most of whom reported using a mix of organisational methods. The majority (71%) used features associated with team nursing (Thomas, 1992). Length of nurse allocation to individual patients appeared to be the most important discriminating factor between task and team methods of organisation. Only two wards used five or more criteria of primary nursing, making it difficult to identify the most important discriminating factors between primary and team nursing. Other authors suggest that the fundamental difference between the two methods involves the level of accountability associated with primary nursing and liaison with other health care staff, both of which are the responsibility of primary nurses while these responsibilities may be shared in team nursing (Ersser and Tutton, 1991; Giovannetti, 1980; Waters, 1985).

A quasi-experimental design was used to identify the effects of team and primary nursing on the activities performed by qualified nurses and nursing auxiliaries in care of the elderly wards, half of which used each method of work organisation (Thomas, 1991; Thomas, 1992). Regardless of ward organisation the majority of nursing time was associated with assisting patients with activities of living. On the primary nursing wards qualified nurses spent 59% of their time in direct patient care compared to 52% in team wards. In the primary nursing wards it was found that nurse-patient interactions focused to a greater extent on giving patients choice related to the care they received. This involved primary nurses spending longer in providing explanations to patients than on wards where team nursing was practiced. Qualified nurses perceived greater autonomy, supervisor support and less work pressure in the primary nursing wards than in the team wards. In addition, qualified nurses reported greater involvement with patients and felt able to be more innovative in practice when conducting primary rather than team nursing. These two factors appeared to be related to the level of control exerted by management, which was perceived by qualified nurses to be less powerful in primary nursing wards than in areas practising team nursing (Thomas, 1992).

Similar benefits were identified by nursing assistants who reported more supervisory support and clarity concerning their roles in primary nursing units than in team nursing areas (Thomas, 1992). Associated with these factors was a perception by nursing assistants that they were able to be more innovative and autonomous within the boundaries set for them by primary nurses than when working with the team nursing method. The positive factors reported by nursing assistants in primary nursing areas were believed to have occurred because they knew how the primary nurses planned and carried out care. The associate nurses were able to carry out work without constant and direct supervision (Thomas, 1992, p.376). Nursing assistants and qualified nurses reported feeling less work pressure in the primary nursing wards. The fact that the primary wards had higher staffing levels may have contributed to this finding, although the increased peer cohesion in primary nursing was a positive contributing factor which influenced the nurses' perception of their work.

Thomas (1992) summarises her findings by stating that the philosophical approach of primary nursing results in a culture which permeates the work of all grades of staff. She acknowledges that primary nursing is not in itself a philosophy; an idea with which others concur (Ersser and Tutton, 1991; Johns, 1992; Pearson, 1988). However, she explains that this form of nursing organisation requires a commitment by nurses based on a philosophical approach embracing an autonomous role for qualified nurses, an individualised approach to care encouraging patient participation and choice, together with an appreciation that nursing involves interpersonal work with patients.

The Burford experiment adopted primary nursing which, it is argued, was one factor in influencing positive patient outcomes (Pearson, 1988). Miller (1985) found that primary nursing, when compared to task allocation, was positively associated with the degree of independence displayed by elderly hospitalised people suffering from mental illness. Most district nurses, health visitors and community psychiatric nurses use individualised patient care approaches, which are associated with the autonomous work behaviour central to primary nursing (Baker et al, 1987; Brooker, 1990). It was the intention that CREST nurses would be required to function in a community based service, with the ability to negotiate with other health care workers, patients and their carers being the most appropriate form of a night nursing service. The recent research which indicated positive benefits to elderly patients in terms of enhanced patient-nurse interaction and increased independence in functioning led to the conclusion that primary nursing should be adopted at CREST (Miller, 1985; Pearson, 1988; Thomas, 1992).

It has been argued that primary nursing requires an all qualified workforce (Marran, 1976). Others acknowledge that in areas when patients are relatively stable for several days at a time the role of primary nurses will include both working with other team members and delegation of some nursing interventions to other staff in their team (Bond and Fall, 1991; Ersser and Tutton, 1991; Fall and Bond, 1991; Johns, 1992; Pearson, 1988). A single case study found recently that it was possible to conduct primary nursing with a nursing assistant population of 45% of the workforce in a ward which provided both respite and acute care for elderly people (Bond and Fall, 1991). Nursing assistants were encouraged to work together with primary nurses either in pairs or under close supervision in the ward, an approach also reported by Thomas (1992). Although it is not possible to generalise from the Bond and Fall (1991) study this is the first work of its kind reported. Other studies imply that nursing assistants are a central component of the primary nursing workforce in areas which provide care for elderly people (Bond et al, 1989; Kitson, 1986; Miller, 1985; Pearson, 1988; Thomas, 1992).

If, as Bond and Fall (1991) report, it is possible to deliver good quality primary nursing care to this client group with a ratio of 55% qualified nurses to nursing assistants, the role of associate nurses will require close examination. Whether effective primary nursing teams for elderly people could be constructed to include only primary qualified nurses and health care assistants, who combine the roles of associate and auxiliary nurse, requires evaluation. Health care managers are increasingly questioning the most cost-effective methods of delivering care, leading to the suggestion that health care assistants who are trained and prepared to work with specific client groups may be able to take on responsibilities previously associated with those of qualified nurses (Robinson et al, 1989; Rowden, 1992). District nurses in some parts of the country function as primary nurses and allocate certain patient care procedures, including bathing, to nursing auxiliaries who undertake those procedures without direct supervision. Boundaries between nursing care which can only be performed by qualified nurses and the forms of care which can be delivered by support workers are open to negotiation (Dalley, 1993). This, coupled with the acceptance that many carers undertake intimate personal care for relatives/friends who have dementia in their own homes, demonstrates that it is essential to investigate further the role of health care assistants in primary nursing teams.

Current literature reveals that extensive work still needs to be conducted to identify the most cost-effective ratios of qualified to unqualified nurses in the delivery of primary nursing to elderly people with dementia. Recently two studies have examined this question in medical and surgical areas. The results indicated that the quality of patient care, in terms of nursing processes and patient outcome, is directly related to the number of qualified staff involved in delivering care (Carr-Hill et al, 1992). The benefits of nursing homes to patients were associated with higher ratio of qualified nurses in the workforce compared to those in long stay wards (Bond et al, 1989).

A relationship between the educational achievements of qualified nurses and the quality of care in wards caring for people with acute psychiatric problems (Armitage et al, 1991) and elderly people with general health problems has been identified (Kitson, 1986). Attempts to identify factors which influence the quality of care in areas where elderly people are nursed have consistently indicated that the ward sister/charge nurse is a key to quality (Evers, 1981; Kitson, 1986; Miller, 1985). Kitson (1986) reported that the orientation and perception of the ward sister was the single most important variable relating to quality. Where sisters had a positive approach to nursing elderly people and placed value on the caring interpersonal function of nursing optimal patient independence occurred with team members respecting and encouraging individuality in patients (Kitson, 1986).

Kitson (1986) also found that these qualities were associated with ward sisters who had had a good post-registration education, had been in post for less than two years and were aged between 30 and 40 years. The extent to which older sisters had been exposed to education was not examined by Kitson (1986) but the growth in post-registration education and the recognition of its influence on patient care has been recent. It is, therefore, surmised that sisters over the age of 40 years in Kitson's study may have been promoted as a result of length of service rather than as a result of adequate preparation and competence. It is also suggested that over the last two decades, more nurses have chosen to work with elderly people, particularly those with dementia, than in the past, when staff may have moved into the area because it was the only opportunity for promotion.

A study of nursing care in elderly wards lead Baker (1978) to conclude that routinised geriatric care occurred when there was a lack of managerial clinical support. She reported that the perceptions, attitudes and morale of staff were the most important factors in influencing the quality of nursing care delivered. Others indicate that the ward sister is the key person in influencing ward environment and thus nursing practice, suggesting that CREST could not function effectively with primary nurses alone but would require a clinical team leader.

Only one study concerning night nursing activity was found which examined the work of qualified and auxiliary nurses at night in medical and surgical wards (NHS Management Consultancy Services, 1987). The mean activity for all grades was as follows: direct care, 37%; indirect care, 31%; unit related work, 19% and miscellaneous, 14%. Similar lengths of time were spent by staff nurses (38%) and nursing assistants (34%) on direct care. Work activity peaked between 2100 and 2300 and 0600 and 0800, reflecting nursing rounds. The report suggested that required staffing levels for night care could be estimated based on patient dependency calculations. Similar approaches which define skill mix based on patient dependency have been developed in care of the elderly areas but they too were based on a functional orientated approach to care (Rhys Hearn, 1979; Wilson-Barnett, 1979). A case study approach in one ward caring for elderly people revealed that nursing assistants and primary nurses were conducting similar work, other than in housekeeping and drug administration duties (Dewar, 1992). This led to the conclusion that the ward was suffering from a skill-muddle, and strengthens the requirement for further research into the area. When developing job profiles for CREST the potential blurring of boundaries between the roles not only of primary and associate nurses but also of nursing assistants required careful consideration.

In 1988 clinical grading for qualified nursing staff resulted in a clinical career structure for nurses (DHSS, 1988b). The advantages and disadvantages of the structure are outside the remit of this review. However, it is important to note that the structure had to be considered when deciding on the appropriate skill mix for CREST.

5.9 Issues relating to managing nursing at CREST

The literature reviewed in this chapter indicates the responsibility managers have in providing organisational frameworks, enabling clinical nurses to provide both good quality nursing care for elderly patients who suffer from dementia and appropriate support and guidance to patients' lay carers. The use of a quality assurance cycle may guide managers in the development of a new nursing service.

Nurse managers have a role in defining and instigating quality monitoring processes in areas for which they are responsible. They should agree a philosophy of care and standards for practice with clinical nursing staff. In particular, managers need to define structural standards, including staffing patterns, and the way in which they expect the organisation of care to be conducted (Smith-Marker, 1988; Fain, 1985). An organisational framework which ensures that managers provide relevant resources for health care and indicates the extent of clinical nurses' authority should enhance the delivery of high quality patient care.

Clinical nurses should, it is argued, have a pivotal role in developing process and outcome standards. Both nurse managers and practitioners need to negotiate the content of standards and when agreement is reached work together towards achieving accepted standards. The emphasis on standard setting pre-supposes that their definition will serve to enhance quality of nurse care, a concept which has yet to be supported empirically (Mawdsley, 1991). Quality assurance programmes should not become so time-consuming and detailed that they constrain practice but rather encourage innovation and autonomy within clinical practice through the systematic processes of reviewing and changing care interventions (ANA, 1982; Kitson et al, 1990; NHS Management Executive, 1993b; Shelley, 1992).

The potential benefits of organising nursing using a primary nursing approach have been explored, leading to the conclusion that this system should be adopted at CREST. There is insufficient evidence to draw conclusions on the best method for devising a cost-effective mix of staff grades within nursing teams for elderly people. However, it is probable that a high proportion of qualified nursing staff is related to high quality care. To optimise care, CREST's clinical leader must have sufficient awareness of a range of knowledge and skills required to provide care to elderly people with dementia and appreciate the need to teach these to staff members (Kitson, 1986).

Clinical nursing practice should be based on up to date knowledge concerning the effectiveness of particular interventions (Audit

Commission, 1992; NHS Management Executive, 1993a; UKCC, 1992). In many instances the knowledge about relationships between specific nursing interventions and patient outcomes is limited (Bloch, 1975; Donabedian, 1966; Green, 1992; Luker, 1981; Marek, 1989). Despite this difficulty nurses should be enabled to update their professional knowledge, therapeutic and technical skills in order to deliver the best care that can be achieved in the light of information concerning issues related to the population for whom they care (UKCC, 1993).

If CREST nurses are to be held accountable for their nursing practice it behoves managers to provide opportunities for staff to attend skill training, continuing education and to have time to review appropriate literature (Armitage et al, 1991; Russell, 1992). The significance of such opportunities is strengthened by Armitage et al's (1991) belief that:

> "Satisfactory outcomes in mental health nursing are significantly dependent on attitudes and behaviour of staff which rest on the level and amount of staff training and continuing education made available."

The attitudes of nurses will influence their clinical behaviours which, in turn, can be positively enhanced through the provision of education. Educational and audit opportunities must be made available to CREST nurses to update their skills and knowledge and allow time for reflection on their practice.

The application of both the nursing process and the Roper et al (1980) model of care, which is easily understood by nurses, other health and social care workers and carers has been demonstrated to assist in the delivery of individualised patient care. For this reason it was recommended that the head clinical nurse at CREST should develop a structured approach to the delivery of nursing, incorporating an activities of living model of nursing (Roper et al, 1980) and a stress-reduction approach to working with patients' carers (Zarit et al, 1985). The nurse researcher involved with CREST was considered to be a clinical expert in the nursing care of elderly people with dementia and was assigned to work with the head nurse prior to the instigation of CREST; this work is described in Chapter 6.

CHAPTER 6

RESEARCH DESIGN AND METHODS

6.1 Introduction

CREST was developed in an inner London Health Authority to increase the range of nursing services for patients suffering from dementia and to provide respite for their carers. The service was jointly funded by the Inner City Partnership Development Scheme and the mental health unit of a London Health Authority. The scheme was initially funded for two and a half years. An evaluation of the service was commissioned to assist the mental health managers in deciding whether to continue funding CREST at the end of that period.

The emphasis on cost-containment within the National Health Service requires that choices have to be made concerning the services that should be introduced, reduced, modified or disbanded (Bond et al, 1989; Culyer, 1985; Department of Health, 1989a, 1993b; Ham, 1992; Overton and Stinson, 1977; St Ledger et al, 1992). Clearly, health care providers cannot develop new programmes and expect purchasers to support them without some evidence of the effects of the new programme. The main objectives of the evaluation were originally to:

a) formulate an operational policy and nursing standards for the service;

b) identify outcomes in terms of patient behaviour and effects on carers of providing a night hospital nursing service;

c) make recommendations concerning future provision of night care in order that both patients' and their carers' needs might be met efficiently and effectively.

The research design and methods used to evaluate CREST are presented in this chapter. The evaluation was conducted in two phases. The first involved formulating an operational policy and standards for practice at CREST (Sections 6.3 and 6.4). The second was the evaluation of CREST which occurred during its first 18 months of operation; the methods used are presented. Finally a summary of the rationale for using a quality assurance single case study design for the evaluation is made.

6.2 Research design

Ethical approval for this project was sought from a London Health Authority ethics committee and granted in November 1988. A case study evaluation design using a quality assurance framework was used to assess CREST. The design involved conducting a thorough in-depth analysis of the service (Bernstein and Freeman, 1975; Peace, 1990; Polit and Hungler, 1991; Suchman, 1967; Walker, 1980). The main evaluation was conducted during the first 18 months of CREST's operation. The time frame was restricted to this period, as the commissioners of the research required a report within two years of the start of the service. This would enable decisions to be made about its future. Funding for the evaluation was therefore only available for the initial 18 months.

Evaluative research involves investigating how well a programme is working (Bernstein and Freeman, 1975; Goldberg and Connelly, 1982; House, 1986a; Luker, 1981; Polit and Hungler, 1991; Smith and Cantley, 1985; Suchman, 1967). The origins of evaluative research are found in large scale assessments of educational programmes (Cronbach, 1982; House, 1986a; Scriven, 1991; Suchman, 1967; Tyler, 1950: Walker, 1980). Initially educational programmes were evaluated using a behavioural approach focusing on student output (Nevo, 1986; Tyler, 1950). The information collected from focusing on outputs was insufficient to explain why some programmes were more successful than others (Bernstein and Freeman, 1975; Cronbach, 1982; House, 1986b; Walker, 1980). In order to answer practical questions concerning the extent to which quality of teaching and curriculum design affected students' ability to pass formal assessments a more comprehensive approach to educational evaluation was developed (Cronbach, 1975; House, 1980 and 1986b; Scriven, 1986; Stufflebeam, 1983; Weiss, 1986).

A comprehensive approach to evaluating educational programmes involves examining the goals, design, process of implementation and outcomes of the programme being studied (Cronbach, 1982; House, 1980 and 1986b; Stenhouse, 1987; Stufflebeam, 1983; Walker, 1980; Weiss, 1972). When evaluating programmes in this way information should be collected concerning the merit of defined goals, the quality and extent of implementation and the worth of outcomes (Cronbach, 1982; House, 1986b; Stenhouse, 1987; Walker, 1980). The assessment of programme worth is an activity consisting of both description and judgement (Bernstein and Freeman, 1975; Guba and Lincoln, 1981; Nevo, 1986; Suchman, 1967). Evaluation research cannot be limited to data collection and objective analysis but requires that information is described and interpreted which involves evaluators in making judgements concerning the merit of programmes being investigated (Cronbach, 1975; Guba and Lincoln, 1981; Nevo, 1986; Suchman, 1967; Walker, 1980).

In order to reduce subjectivity when conducting evaluative research it is essential to plan the evaluation to determine the kind of information which should be collected and how it should be analysed (Bernstein and Freeman, 1975; Guba and Lincoln, 1981; Suchman, 1967). One model of educational evaluation focuses on four programme variables; goals, design, process of implementation and outcome (Stufflebeam, 1983). Stufflebeam (1983) suggests that programme evaluation should be designed so that information can be collected concerning the merit of goals, quality of plant, the extent to which plans are carried out and the worth of outcomes. The merit or worth of outcomes can only be judged in the specific context of the object and function of the programme under evaluation (Guba and Lincoln, 1981; Nevo, 1986; Stufflebeam, 1983; Suchman, 1967). Evaluative research can never be value free, because in order to make valid judgements those involved in the evaluation need to have an understanding of the subject under investigation (Cronbach, 1972; Guba and Lincoln, 1981; House, 1986b; Suchman, 1967). Although a systematic approach to investigation can reduce subjectivity, by focusing on collecting accurate information, the judgements made about qualitative information collected in an evaluation will be affected both by the requirements of commissioners of the evaluation and the evaluators' values, attitudes and past experiences (Cronbach, 1982; Guba and

Lincoln, 1981; House, 1986b; Suchman, 1967; Weiss, 1986). When conducting practical evaluations of any service the perspectives should be acknowledged in order that the results can be interpreted in the context of those perspectives (Guba and Lincoln, 1981; Stronbach, 1987; Suchman, 1967). Stronbach (1987) suggests that unless such a pragmatic approach to evaluation is taken no evaluations would ever occur, because of the difficulty of eliminating subjectivity. Evaluation research in education has developed from a behavioural approach to a comprehensive systematic method of enquiry which focuses on the structure, processes and outcomes of the programme being investigated (House, 1986b; Nevo, 1986).

Evaluative research has spread from education into other fields including health care (Marsland and Gissane 1992; World Health Organisation, 1981). In 1981, the World Health Organisation (WHO) emphasised the importance of health programme evaluation. WHO (1981) stressed the value of rigorous planning prior to instigating an evaluation so that systematic information and valid indicators of effectiveness can be collected concerning the programme being examined. More recently the Department of Health's (1993b) strategy for research and development has endorsed the value of evaluative research in health care.

In the context of the health service St Ledger et al (1992) define evaluation as:

> "The critical assessment, on as objective basis as possible, of the degree to which entire services or their component parts (e.g. diagnostic tests, treatments, caring procedures) fulfil stated goals." (p.1)

The reference to goals makes explicit a demand that health care evaluation requires comparison of the outputs of a service with standards as described in educational evaluation. Standards can be either absolute or comparative. A comparative standard is used to ascertain whether a specific intervention would be an improvement on existing services (Bernstein and Freeman, 1975; Cronbach, 1987; Department of Health, 1993b; Guba and Lincoln, 1981; St Ledger, 1992). A comparative evaluation was not performed for this study because there was no night service with which CREST could usefully be compared. An absolute standard is used to evaluate a service against its stated aims (Department of Health, 1993a,b; Guba and Lincoln, 1981; Luker, 1981; Suchman, 1967; Weiss, 1986). The aims of CREST were as follows:

a) To provide, as part of the comprehensive community orientated mental health services for a London District, support for elderly mentally confused people and their families at night.

b) To provide relief for relatives who care for elderly mentally infirm people at home. The night hospital would give the opportunity for relatives to have a night free from caring, allowing them to rest or socialise undisturbed.

c) To provide individualised programmes of care for each patient at night which are orientated towards facilitating their independence and dignity.

d) To provide a service which supports informal carers by working in partnership with them to deliver high quality care to patients.

The CREST service was evaluated against these aims using a multi method approach.

The second key element in the definition of health care evaluation is objectivity (Department of Health, 1993a,b; Luker, 1981; St Ledger et al, 1992; Smith and Cantley, 1985). Assessments should be as independent as possible from the judgements and prejudices of both the evaluators and those who commission health care evaluation. It is acknowledged that total objectivity is impractical and undesirable, since judgement always plays some part in evaluation (Challis and Darton, 1990; Cronbach, 1982; Guba and Lincoln, 1981; St Ledger et al, 1992; Suchman, 1967). When judgements are made in defining the reference of an evaluation, selection of measurement procedures and interpretation of findings those judgements should be made explicit and thereby open to criticism (Challis and Darton, 1990; Cronbach, 1982; Smith and Cantley, 1985; St Ledger et al, 1992; Suchman, 1967; Walker, 1980).

Evaluative research is value laden because values influence the orientation of the pre-stated goals against which evaluation is conducted (Challis and Darton, 1990; Suchman, 1967). Indeed, where a quality assurance approach to health care evaluation is adopted, identification of values is the first step in defining possible criteria for measurement (ANA, 1982; Donabedian, 1969; RCN, 1987; St Ledger et al, 1992). The night hospital nursing service was developed and run by nurses and the evaluation conducted by nurses. The underlying values of the discipline of nursing and the nursing framework developed to guide practice in CREST influenced the aims of the service against which it was evaluated. Had the service been developed by social workers or doctors it is possible that their values would have resulted in different pre-stated goals of the service.

Evaluative research involves determining the relationship between the achievement of pre-stated goals and the service under investigation (Cronbach et al, 1982; Guba and Lincoln, 1981; St Ledger et al, 1992; Suchman, 1967; Walker, 1980). This suggests that it is possible to isolate the factors to be measured and explain, at least to some extent, the relationships between factors. In health and social care evaluation it is rarely possible to establish causal links between nursing interventions and patient outcomes (Bergman and Golander, 1982; Bloch, 1977, 1980; Bond and Thomas, 1992; Challis and Darton, 1990; Crow, 1981; Department of Health, 1993b; Dickoff and James, 1968; Heater et al, 1988; Lindeman, 1976; Nicholls and Wessells, 1977; Wessells and Klein, 1977; Wright, 1984). This is because patients are exposed to many therapeutic inputs when nursed in hospital, including medical treatment, physiotherapy, occupational therapy and other individualised interventions, such as special diets, counselling and peer support. When patients use community based nursing services additional variables including family support, the quality of their living accommodation and financial factors will also contribute to outcomes. Another reason that it is so difficult to attribute individual patient outcomes to specific nursing actions is because each patient has different personal characteristics which will affect their responses to care. Knowledge is never complete and there will always be gaps in the cause/effect sequence which can only be filled by making judgements concerning the potential relationships between nursing actions and patient outcomes (Bernstein and Freeman, 1975; Bloch, 1977, 1980; Closs and Tierney, 1993; Donabedian, 1969, 1970; Luker, 1981; Stronbach, 1987; Suchman, 1967).

Using an experimental approach to health care evaluation and comparing the outputs of two services with similar aims can assist in establishing causal links between inputs and outcome (Challis and Darton, 1990; Challis and Davies, 1983; Cronbach, 1982; Department of Health, 1993b; Suchman, 1967; Walker, 1980). An experimental approach could not be undertaken at CREST because the health authority considered it unethical to withhold the service from potential patients, and as stated earlier there was no night service with which a comparison could be made. Therefore, a case study design was used.

See additional para next page

It was recognised that the case study approach involved "examination of an instant in action" (Walker, 1986, p.33) which would provide a study of incidents and events during the period investigated. The best case studies utilise both qualitative and quantitative approaches to information collection so that the results retain a coherence and complexity and enable a clear illustration of the subject of study to be developed (Guba and Lincoln, 1981; House, 1986, 1987b; Smith and Cantley, 1985; Van Manen, 1990; Walker, 1986). This study adopted a predominantly

\# Additional paragraph

The scientific and educational approaches to case study design were considered when selecting the method for evaluating CREST. The scientific approach is conducted 'in conformity with science's goals and methods' (Campbell in Yin, 1984, p.9). It is advocated that five components of research design are important:-

1) a study's questions;
2) its propositions, if any;
3) its unit(s) of analysis;
4) the logic linking the data to the proposition; and
5) the criteria for interpreting the findings.

(Yin, 1984, p.29)

This design has developed from experimental psychology and focuses on formulating research questions concerning how and why the unit of investigation operates. This rigorous scientific approach is particularly appropriate when the investigator has little control over the events of the 'case' and wants to focus on contemporary phenomena within a real-life context (Yin, 1984). This approach was not totally appropriate for the CREST evaluation because the investigator was involved in developing operational policies and had some control over the structure and process of the service. Rather, the focus of the CREST investigation involved examining the extent to which the service conformed to or was constrained by the operational policy and the effects of the service on patients and their carers. Yin (1984) argues that when the goals of evaluative research include describing and identifying predictive pathways relating to certain outcomes, a survey strategy has advantages over a case study.

The educational evaluation case study method (House, 1980/1986; Walker, 1980) does not distinguish between the survey and case study approach in the rigorous scientific manner described by Yin (1984) but takes a more eclectic approach incorporating survey methods. This approach to the case study evolved within a system in which evaluators are involved in designing the programmes under investigation, as was the case with CREST. Therefore, it was decided to adopt the educational case study approach to the evaluation of CREST while, at the same time, ensuring that the systematic approach to research design advocated by Yin (1984) was incorporated within the design. The CREST service was perceived as a 'single case' or unit for evaluation with four data sets; patient activity, nurse activity, patient and carer outcomes being analysed independently as sub-units. Defining the CREST service as the 'case' and the sub-units of analysis enabled the data to be linked logically to propositions and criteria so that results could be interpreted in a systematic manner.

qualitative approach. Consideration was given to the rigour of the research process. Case studies which use qualitative methods can be enhanced by using rigorous approaches to investigation which are clear and explicit (Dey, 1992; Field and Morse, 1985; Guba and Lincoln, 1981; Kirk and Miller, 1986; Suchman, 1967; Walker, 1980, 1986). Guba and Lincoln (1981) assert that validity, reliability and objectivity are appropriate tests of rigour when the scientific paradigm is used but that different factors indicate rigour in naturalistic research. They propose certain analogous terms as more appropriate to the naturalistic paradigm (Figure 6.1). Where auditability, truth value and applicability are established it is argued that confirmability is achieved (Guba and Lincoln, 1981). This study focused on considering these three criteria of rigour.

ASPECT	SCIENTIFIC TERM	NATURALISTIC TERM
Truth value	Internal validity	Credibility
Applicability	External validity/ generalizability	Fittingness
Consistency	Reliability	Auditability
Neutrality	Objectivity	Confirmability

Figure 6.1 Scientific and naturalistic terms appropriate to various aspects of rigour (Guba and Lincoln, 1981)

When planning an evaluation it is necessary to consider what can be done to produce findings most likely to be found credible by sources and how credibility can be tested within sources (Guba and Lincoln, 1981; Kirk and Miller, 1986). Carers were interviewed about the effects of CREST on themselves, rather than, for example, asked to complete a questionnaire. The interviewers were able to cross-check the data they collected with carers making the study more credible (Chapter 6, Section 6.7.5). In addition non-participant observation of nurses' and patients' activity at CREST was collected for three separate time periods. This allowed cross-checking of the information collected between periods and respondents (patients and nurses). Cross-checking can improve credibility by identifying both convergence in and conflict between data sets (Guba and Lincoln, 1981; Kirk and Miller, 1986). Careful data recording can also improve the probability of credible findings, a factor which was considered of paramount importance when conducting this study (Denzin, 1978; Guba and Lincoln, 1981; House, 1980, 1986).

The assessment of fit in an evaluation requires that both the researcher and those who review the results are sufficiently knowledgeable about the subject under investigation to judge the applicability of the results (Guba and Lincoln, 1981). A study meets the criterion of fittingness when the findings are meaningful and applicable to the audience in terms of their own experience (Guba and Lincoln, 1981; Sandelowski, 1986; Van Manen, 1990). A case study should present the findings in such a way that the descriptions and explanations of identified patterns are clearly derived from the data collected (Guba and Lincoln, 1981; Walker, 1986). The evaluator and interviewers were experienced mental health nurses with a special interest in care of elderly people, they therefore fulfilled the criterion of being knowledgeable about the subject under investigation.

Auditability is the criterion of rigour which Guba and Lincoln (1981) propose relates to consistency in qualitative research. They suggest that if a study is presented sufficiently clearly and including the appropriate raw data, another researcher should be able to follow the evaluator's "decision trail" (Guba and Lincoln, 1981, p.122). This requires that the auditor judges whether research is conducted competently in terms of the way in which data are used to iterate and develop descriptions and patterns concerning the subject. Therefore it was decided to build a rich picture of the CREST service when reporting the results to assist the audiences in their scrutiny of the way in which descriptions, patterns of attendance and outcomes relating to CREST were developed (Checkland, 1984; Van Manen, 1990; Walker, 1986). The difficulties of making judgements about cause and effect in single case studies are so great that Walker (1986) states:

> "Case studies should present contingency relationships only, leaving the audience to infer cause." (p.58).

It was anticipated that by describing the CREST service in detail and subsequently observing the service in action there would be sufficient information collected to classify how the service actually operated (Guba and Lincoln, 1981; Stufflebeam, 1983; St Ledger et al, 1992; Stufflebeam, 1983; Van Manen, 1990; Walker, 1980). This information could then be considered in relation to patient and carer outcomes, which would be measured at periods during patients' attendance at CREST. Finally, judgements concerning potential relationships between CREST activity and outcome would be formulated by classifying and linking the information collected (Cronbach, 1982; Dey, 1992; Guba and Lincoln, 1981; Suchman, 1967; Walker, 1980). The aim was to produce a case study of CREST which approached a good phenomenological description, where the results seemed to be true to those who had not conducted the evaluation but had an understanding of the subject investigated. If this is achieved in a case study rigour is demonstrated (Guba and Lincoln, 1981; Kirk and Miller, 1986; Van Manen, 1990; Walker, 1980).

6.2.1 Defining structure, process and outcome factors

A structure-process-outcome quality assurance framework was used for the evaluation of CREST. The framework was based on the work of the American Nurses' Association (1982), Bloch (1975 and 1977), Donabedian (1969 and 1970), Kitson et al (1990) and the Royal College of Nursing (1988); their work is reviewed in Chapter 5 Section 5.1. This framework was used to assist in the identification of factors which may contribute to patient and carer outcome.

Evaluations of nursing have tended to focus on measuring outcomes with structure and process left assumed or undefined, making it impossible to link outcomes to particular nursing inputs (Luker, 1981; Thomas and Bond, 1990). As early as 1977 Bloch argued that an essential responsibility of nurses involved in evaluation was to begin to identify the relationships between structure, process and outcome. One reason that nursing research has tended to focus on evaluating outcomes may be because there are conceptual difficulties in the isolation of the three aspects (Closs and Tierney, 1993; Davidson, 1977; Goldstone and Doggett, 1990; Jennings, 1991; Luker, 1981). It has been argued that "distinguishing among structure, process and outcome is basically an abstraction" (Jennings, 1991). There are undoubtedly circumstances when this is true, and it can be particularly difficult to differentiate between structure and process factors. For example, when a manager is expected to undertake a certain action, for instance, to provide an ambulance for CREST, this action could be categorised as a "process". Alternatively the action could be categorised as a structural factor involving the supply of equipment. In reality the categorisation in this example will rest on the judgement of those involved. There must therefore be agreement among people involved in health care evaluation concerning the perspectives from which categorisation of factors into structure, process and outcomes are made (Closs and Tierney, 1993; Donabedian, 1966).

The aim of this study was to collect data which would reveal information concerning the relationships between the way in which CREST was structured, nursing actions and patients' and carers' outcomes. This could only be achieved if at least some attempt was made to isolate structure, process and outcome standards in the way described by ANA (1982), Bloch (1977), Donabedian (1969) and the Royal College of Nursing (1988). For the purpose of this study the author, in consultation with the managers who commissioned the research, defined boundaries for categorisation. It was decided that structural standards would be defined using the nine elements described by Smith Marker (1988) (Chapter 5 Section 5.1). In addition, equipment and environmental factors, for example lighting, would be included in this category. Process standards were defined in terms of the activities expected of nursing staff when caring for patients (Bloch, 1977; Kitson et al, 1990). The parameters for categorisation of structure and process standards were clearly delineated. Managers' responsibilities and actions would be considered "structural" factors and CREST's clinical staffs' responsibilities and actions "process" factors. Outcome factors were defined from patients' and carers' perspectives. In addition, patient activity at CREST would be defined in terms of outcome rather than process.

6.2.2 Two phases of evaluation

The design of the evaluation consisted of two phases: first, the formulation of structure and process standards and secondly, collecting data once CREST had opened. In the first phase structural and process standards for CREST were defined and agreed by a project management team, including the author and charge nurse appointed to CREST (Sections 6.2 and 6.3). The second phase of the evaluation was concerned with identifying the way in which CREST actually operated, and collecting patient and carer outcome data (Sections 6.4 to 6.9).

6.2.3 Defining the terms

Terms were defined as follows for the purpose of this evaluation:

a) CREST committee - the project team as defined in 6.3.1 who became the operational committee (Chapter 7, Section 7.1).

b) Nursing staff - all qualified nurses, nursing assistants and the ambulance driver who also had a clinical role.

c) Primary nurses - a registered mental health nurse on part 3 of the UKCC register (RMN) who was responsible for individual patients' care as detailed in Chapter 5 Section 5.

d) Associate nurses - qualified nurses on either part 2 or part 4 of the UKCC register who conducted care in the absence of an individual's primary nurse.

e) Nursing assistant - a member of the nursing team who was involved in both clinical, driving and housekeeping duties. Nursing assistants were expected to work under the supervision of qualified nurses.

f) Patients - any person who was accepted at and attended CREST.

g) Carer/caregiver - the relative or friend who held primary responsibility for providing care and support to a CREST patient at home.

h) CREST - the night hospital nursing service which is the focus of this evaluation.

6.3 Defining structural standards

6.3.1 The project team and initial planning

The first meeting of the project team took place seven months before CREST opened. Membership comprised the following:

director of nursing services (Chair);
consultant psychogeriatrician (who supported CREST);
nurse manager for community psychiatric nursing;
unit personnel officer;
member of the Community Health Council;
head occupational therapist;
clinical nurse manager (special duties);
senior charge nurse, psychogeriatric day hospital;
head of ancillary services;
project evaluator.

At the meeting the author outlined the proposed service. The team considered the possible location of the service. The geriatric day unit in a small elderly-care hospital was favoured. This unit was part of the community unit. At that time the mental health and community units were both directly managed by the health authority;

negotiations, therefore, should have been straightforward. The consultant psychogeriatrician offered to organise emergency medical cover for the service, which would be based three miles from the main mental hospital. This demonstrated his commitment to the project and to multi-disciplinary working in order to provide high quality care to elderly people with dementia. One medical consultant rejected the notion of a night hospital service because it was led by nurses rather than by medical staff.

The initial operational plan was agreed as follows:

a) The service would open in January 1989.

b) A maximum of 15 patients would be accepted per night.

c) The service would operate each week from Monday to Thursday.

d) The service would be open to all residents of the neighbourhood serviced by the health authority.

e) There would be an open referral system.

f) All people referred would be visited at home by the charge nurse of the service to assess its suitability and relevance to each individual.

g) All nurses in CREST would be required to hold clean driving licences so that they could drive the ambulance.

It was decided that a charge nurse should be recruited and appointed as soon as possible. This was to enable the post-holder to recruit other staff and to draw up detailed policies concerning nursing in the unit. The director of nursing services suggested that the author would have a key role in developing the draft operational policies for discussion by the project team. The author would service the project team, prepare agendas and minutes and work with team members to develop draft standards and policies for discussion.

At the second meeting two issues were discussed in detail: the proposed site and the projector evaluator's post. It was reported that the hospital special trustees had agreed to fund the position of project evaluator. A draft job description was circulated and agreed, and the personnel officer was asked to advertise the position within the health authority. The post would be for 20 hours per week commencing on 1 September 1989 for a fixed period of two years.

6.3.2 Service site

The CREST site would continue to be used as a geriatric day unit service from 9.00 a.m. to 5.00 p.m. Monday to Friday. As a result the following issues had to be resolved:

> Cleaning: this took place at 7.00 a.m. and would need to be rearranged.
>
> Security: the site was shut and locked at 5.00 p.m. A system had to be devised to enable CREST nurses to collect and hand over keys.
>
> Patients' records: these needed to be held securely in limited space.
>
> Beds: would have to be obtained that were safe and comfortable for patients but also easily stored in one room during the day.
>
> Privacy: patients would need to sleep in the dining area. Adequate screening to maintain privacy would be needed.
>
> Lighting: fluorescent strip lighting would not be suitable for use at night. Dimmed lighting was required.

All these issues were resolved. It was difficult to find beds which would be both comfortable and easily stored. Eventually large Z-beds which could be folded away at night were specially designed by a hospital supplier.

Advantages of the proposed site were the availability of baths, showers and toilets specially designed to promote independence, as well as to assist nurses in delivering hygiene care when necessary. There were hairdressing and recreational facilities including an art room and small kitchen where drinks and snacks could be made by patients and nurses. Three small rooms could be used for patients to sleep separately, and the dining area could accommodate beds for up to nine patients, subject to the availability of screens to ensure privacy. Three more beds could be placed in the physiotherapy room if more than 12 patients attended on one night. Patients who were to sleep in the dining area would be encouraged to change into night and day clothes in bathroom areas rather than by their beds. Because the site was located centrally within the area served by the health authority patients would not have to travel far between CREST and their homes.

6.3.3 Drafting and agreeing the operational policy (structural standards)

The author and the project team prepared draft operational policies for the unit. These were revised following consultation with the general manager, a community health council representative and members of a carer group, which met in the psychogeriatric day hospital. The final draft of the operational policy (Appendix 6.1) contained the service aims and philosophy (Figure 6.2) and broad structural standard statements (Kitson et al, 1990), which included many of the factors defined by Smith-Marker (1988). Some more specific standards were defined: for example, the number of staff who were to be on duty at particular periods throughout the night (Appendix 6.1, No.9). The policy stated the responsibilities of managers for providing clinical nursing staff with the resources to conduct care in a similar manner to the "Maudsley philosophy and standards" (Russell, 1992). The project team believed that the operational policy provided clear indications for staff of what would be expected of them, while being broad enough to encourage autonomy and innovation in delivering nursing care. Four months before CREST opened the operational policy was accepted by the unit management team. It was subsequently agreed by the health authority Strategy and Resource Committee.

The author was then officially appointed as the project evaluator. Initially, three outstanding issues had to be resolved concerning CREST's operation and the author's assist once in the selection and preparation of staff. The issues were: patient transport, structural work required to prepare the unit for patients at night and medical cover.

The provision of transport was extremely difficult to organise. It was necessary to find an ambulance which could transport at least 12 patients and which had a hydraulic tail-gate lift and wheelchair clamps. The London Ambulance Service stated that they were unable to provide the kind of service that was required. It was decided that the most cost-effective option would be the use of one of the mental health unit's ambulances, which was mainly used for patients attending the psychogeriatric day hospital. The main disadvantage of this was that CREST staff would have to go to the main psychiatric hospital to collect the ambulance and return it the following morning.

AIMS

1. To provide, as part of the comprehensive community orientated mental health services for a London District, support for elderly mentally confused people and their families at night
2. To provide relief for relatives who are caring for elderly mentally infirm people at home. The Night Hospital will give the opportunity for relatives to have a night free, allowing them to rest or socialise undisturbed
3. To provide individualised programmes of night care for each patient, which are orientated towards facilitating patients' independence and dignity
4. To provide a service which supports informal carers by working in partnership with them to deliver quality care to patients

PHILOSOPHY

1. Patients should be able to remain in their own homes for as long as possible, cared for by relatives and friends who are, in turn, supported by the statutory health services
2. Where a sitter service would be deemed more appropriate, owing to a patient's frailty, the Night Hospital staff will arrange appropriate referrals to voluntary and statutory agencies
3. The service will be developed around the individual needs of patients and their families. Each patient will have an individualised treatment programme using a nursing intervention approach. The key objective of the service is to meet the patient's needs

   Nursing staff will be committed to taking a completely realistic approach to patients' needs and be aware of the contribution both statutory and voluntary services can make to their patients' health
4. Patients will receive care and treatment in the least restrictive setting with as much freedom as possible
5. Patients will have the right to personal privacy
6. Patients will have the right to be addressed with courtesy and respect at all times, and to be addressed as they choose

Figure 6.2 Aims and philosophy of the CREST night nursing hospital

The fire officer advised that an extra fire door was necessary, as patients would sleep in the dining area. Advantages of this door were that it would both increase privacy and reduce draught. When it was constructed, staff who worked in the unit during the day objected to the door because, unless propped open, it would reduce accessibility to the dining room for patients in wheelchairs and those using walking frames. A compromise was reached when a safety catch was attached to hold the door open during the day.

It was agreed that emergency psychiatric medical cover would be provided to the service by the on-call registrar for elderly patients in the main hospital. This agreement was reached at the hospital medical committee in November 1989 after lobbying from the general manager and the psychogeriatrician, who was a member of the project team.

6.3.4 Job descriptions and shift systems

It was unit policy to advertise all new posts internally, as the gradual reduction in the size of the hospital meant that staff were at risk of staff job losses. The author made a special case for the charge nurse post, arguing that the quality of clinical leadership in CREST would be a vital factor in terms of both marketing the service and assuring a high standard of nursing care. The literature reviewed in Chapter 5, Section 5.3 was used to support her argument, which the general manager accepted.

The G grade charge nurse job description was agreed and advertised in July 1988 (Appendix 6.2). The person appointed held the following qualifications: RGN, RMN, Diploma in Nursing (London

University), Diploma in Nursing Education (London University). She had experience of working as a nurse teacher. At the time of interview she had been working for a year as a night staff nurse in a ward caring for elderly people with dementia. She had had a career break, and was keen to seek promotion on night duty.

The charge nurse was appointed from 1 October 1988, allowing her three months to prepare the service. At first she helped in developing job descriptions for the unit's staff; since these needed to reflect the operational policy and nursing standards she developed these concurrently.

The shift systems for staff were agreed as follows:

A 7 p.m. - 11.30 p.m.	4.5 hr/night
B 11.30 p.m. - 9.30 a.m.	9 hr/night (to include 1 hr break)
C 8.00 p.m. - 8.00 a.m.	11 hr/night (to include 1 hr break)
D 9.30 p.m. - 9.30 a.m.	12 hr/night (to include 1 hr break)

The grade mix was broken down as follows.

Grade	Positions	Whole time equivalents
G	one full time	1
E	one full time	1
D	one full time two part time	1.96
C	one full time one part time	1.48
A	one part time	0.48

It was anticipated that the skill and grade mix would allow for one primary nurse and one associate nurse to be on duty at all times. The E and D grade posts would carry primary nursing status, and the C grade posts were associate nurses. Although it had been decided that all nurses should be able to drive the ambulance, the project team thought that the nursing assistant (Grade A) should take prime responsibility for this. The post would be for 22 hours per week, 7 p.m. - 10.30 p.m. and 7.30 a.m. - 9.30 a.m. The nursing assistant would collect the ambulance and meet the nurse on a C shift at CREST at 8 p.m. They would then collect the patients. The nurse on D shift would be at CREST to receive any patients brought in by their carers and to prepare for the arrival of patients transported by ambulance.

Once agreed, the posts were advertised first within the mental health unit and then nationally. At interview staff were assessed against a person specification, which distinguished between primary and associate nurses in one clause (Appendix 6.3), relating to knowledge and experience of planning individualised care. The primary nurses would be expected to take overall responsibility for planning care, while the associate nurses would assist in the delivery of nursing care. All the posts except for 20 hours of grade C time were filled and staff were appointed from 1 January 1989. The Grade C vacancy was held open so that grade mix could be altered if necessary once CREST was running.

6.4 Nursing standards and framework for practice (process standards)

A pre-requisite for the evaluation was that the nursing standards and the framework for practice were defined from the inception of the service.

The author devised a framework for nursing care incorporating both Zarit's and Roper's approaches (Roper et al, 1980; Zarit et al, 1985). The framework was presented to 20 community nurses, who were involved in supporting people with dementia in their own homes, and their opinion was sought. They all reported that they used a stress reduction approach to their practice. This, they said, involved both giving information and encouraging people to choose preferred ways to look after their relative or friend with dementia. The main difference they perceived between the author's framework and their community nursing practice was that they did not use a structured approach for identifying patient problems, but used activities of daily living as the focus. The CREST charge nurse was enthusiastic about the proposed framework for care but felt Orem's model (Orem, 1985) could be more usefully combined than the Roper model with Zarit's framework. After discussion with the Director of Nursing Services it was agreed to adopt the author's framework (Figure 6.3). Because Roper's model was used by the other elderly care services in the unit, it was argued that CREST patients' nursing care plans would be more readily transferred and understood by other nurses within the unit than if the Orem model was combined with a stress-reduction approach.

The DySSSy approach to developing standards (Kitson et al, 1990) was used by the charge nurse. Each nursing standard contained a statement describing its broad objective, together with several process criteria. The associated structure criteria were considered to be implicit within the operational policy. The patient's outcome criteria were to be measured as part of the project evaluation.

STRESS MANAGEMENT/ACTIVITIES OF LIVING MODEL

Although a trained nurse can rapidly assess a patient's nursing requirements using an activities of living model of nursing, to do this in isolation from the caregiver would be insensitive and irresponsible.

One method of identifying priority problems for the family unit and planning support for informal caregivers is the dementia stress management model (Zarit et al, 1985).

The Dementia Stress Management Model

This is a two-stage model that aims to minimise stress of the caregiver:

Stage 1	Information giving
Stage 2	Problem solving

In **STAGE 1** the nurse gives carers information about the patient's disease and the availability of resources to support them.

In **STAGE 2** the problem solving cycle is broken down into a series of steps and used to help resolve problems caused by a person with Alzheimer's disease in any family unit.

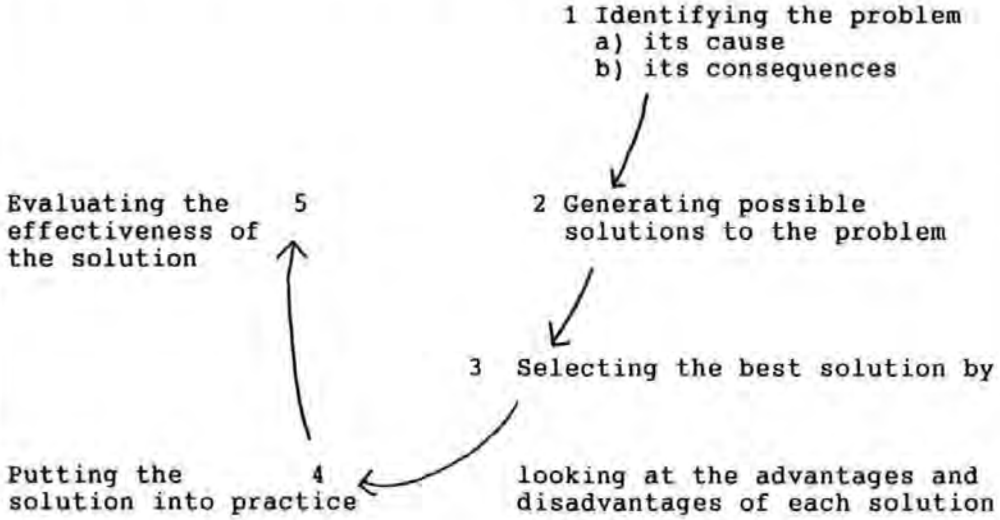


Figure 6.3 The Nursing Framework designed for use at CREST (continued)

Patient Orientated Needs Identification Using an Activities of Living Model

The activities of living model can be used by the nurse and carer to assess the patients' ability to carry out their activities of living and to define actual problems:

Maintaining a safe environment
including memory & orientation
Eating and drinking
Personal cleansing and dressing
Controlling body temperature
Expressing sexuality
Memorising
Dying

Communicating
Breathing
Eliminating
Mobilising
Working & playing
Sleeping
Perceiving

(Watkins, 1987b after Roper et al, 1980)

Carers can be helped to reveal patient behaviours that cause them most distress using the above headings as guides. The majority of caregivers report finding certain problems more difficult to cope with than others. For example, most carers can tolerate a patient's inability to dress and walk unaided, but 60% find it difficult to cope with inappropriate urination and verbal abuse from the sick person.

Aims of Nursing/Selection of Solution

Having identified the patients' problems, care can then be organised with the aim of nursing to:

maintain/increase patients' independence, while ensuring patient comfort;

reduce carers' stress.

It is important that both the nurse and carer are involved in the selection of a solution, as frequently the carer will be involved in its implementation. (For example, with a continence promotion programme.)

Implementation

The selected solution is then implemented by the nurse in the Night Hospital and in some cases at home by the carer.

Evaluation

Finally, the nurse and caregiver evaluate the outcome of the chosen solution. If the strategy is successful, it should continue; if not, the problem solving cycle is recommenced.

Figure 6.3 (continued) The Nursing Framework designed for use at CREST

Outcome criteria, therefore were not specifically defined within each nursing process standard as recommended by the DySSSy approach. The nursing standards encompassed the use of primary nursing, individualised patient care planning and contained specific standards relating to care management. The standards reflected the aims and philosophy of the service as agreed by the unit management team. It was predicted that even a relief nurse visiting the unit for a single shift would be able to use them. For these reasons, the standards were approved by the project team (Figure 6.4).

Fain's (1985) argument that managers should establish a vision for a service and identify the boundaries within which workers should practice appeared to be of some benefit: the charge nurse commented that she found the operational policy a useful guide when developing the standards.

INFORMATION ABOUT STANDARDS

All nurses working in the night hospital are aware of the standards of nursing care, have read them and been given their own copies.

ASSESSMENT

Each patient referred to our service is visited at home, by a member of the nursing team, to assess suitability for attendance prior to admission.

Assessment is normally conducted in conjunction with all members of the community multi-disciplinary team involved in the care of the patient. When admission is deemed to be necessary immediately, and liaison with all members of the multi-disciplinary team has not been possible prior to admission, liaison takes place as soon as possible afterwards.

Each patient is asked during assessment what form of address she prefers. If she is unable to make her wishes known, her carer is asked. The name given is recorded and always used.

PRIMARY NURSING

Each patient has a primary nurse who is responsible together with associate nurses, for planning and delivering their care.

The patient's primary or associate nurse introduces herself to the patient at the beginning of her span of duty and at intervals throughout.

In the absence of the primary and associate nurses for an individual patient, any nurse may attend to any patient. This applies for a whole span of duty, for part of a span of duty, e.g. during a meal break, or when the patient's own nurse is occupied with another patient.

Figure 6.4 CREST's Nursing Standards (continued)

CARE PLANNING

Each patient has their own individualised care plan which is in operation by the nurse's fourth night's attendance at the latest.

Individual assessments are completed using a stress management/activities of living model of the nursing process, in co-operation with the patient's carers.

Clear patient goals are identified and recorded on the care plan.

Each individualised care plan is evaluated at least once every four weeks, or by the eighth night's attendance, whichever is the sooner. Evaluations are carried out in consultation with carers.

MANAGEMENT OF INCONTINENCE

Incontinence is not regarded as the inevitable consequence of ageing.

If the general practitioner has not already investigated the causes of incontinence this is requested prior to admission, or as soon as possible after admission.

Appropriate medical treatment for problems related to incontinence is given when prescribed, in conjunction with the carer.

When medical treatment is not prescribed or has been completed, and incontinence persists, this is treated by nursing measures.

Each patient has their incontinence needs assessed during care planning and appropriate nursing measures are prescribed by their primary nurse.

All patients who are incontinent have clear nursing orders in their care plans for the treatment and/or management of this problem.

PREVENTION OF PRESSURE SORES

On admission, every patient is assessed with the Norton Scale for susceptibility to pressure sores.

Reassessment with the Norton Scale takes place every time the care plan is evaluated, the onset of physical illness and at any time that the patient's health is considered to have deteriorated.

Every at-risk patient has an individualised care plan for the prevention of pressure sores.

Pressure relieving aids are always available and are used for all at-risk patients who are assessed as being in need of them by their primary nurses.

Figure 6.4 (continued) CREST's Nursing Standards

PERSONAL HYGIENE

The personal hygiene needs of each patient are discussed with the patient and the carer prior to admission.

Whenever possible the patient looks after their own personal hygiene needs with a minimum of help from nursing staff.

All patients are bathed while in the night hospital, at least once a week, unless the patient and their carers prefer to make their own arrangements.

Each patient decides when and how they are bathed.

Each patient who is incapable of looking after their own personal hygiene needs is washed thoroughly or bathed every morning, unless they refuse.

Carers are always informed if patients refuse to be washed.

FREEDOM OF MOVEMENT

Patients decide when they wish to go to bed, and are never woken before 7.00 a.m.

When it is impossible to persuade a patient to go to bed, they are allowed to spend the night reclining in a chair. Blankets and pillows are provided for warmth and comfort.

REALITY ORIENTATION

24 hour reality orientation is practised. All staff understand the full implications of reality orientation and participate in its practice.

Formal sessions of reality orientation and reminiscence therapy are available for any patient requiring them, but no one is forced to participate.

GENERAL

Every effort is made to maintain the dignity and privacy of each patient in our care.

The cultural and religious needs of all patients should be met.

Figure 6.4 (continued) CREST's Nursing Standards

6.5 Evaluating the CREST service

Non-participant observation, the Crichton Visual Analogue Scale, interviews and retrospective review of patients' nursing notes were used to collect data in the second phase of the evaluation of CREST. It was necessary to identify whether CREST operated in line with the operational policy and nursing standards so that judgements could be made about the relationships between structure, process and outcome. Data concerning changes which were made to operational policy and nursing standards in the first year of CREST's operation were collected by the author attending CREST management team meetings. In addition, non-participant observation of nursing staff activity was conducted to identify peak workload periods and the extent of adherence to nursing standards. Non-participant observation of patient activity was conducted by the author in an attempt to identify whether nursing activity facilitated patients' independence and comfort.

A retrospective review of patients' nursing notes was conducted to identify whether the nursing framework for practice (Figure 6.3) was used when assessing planning, implementing and evaluating care. Carers were interviewed to identify the effects on them of their relative or friend attending CREST. At these interviews carers were also asked to identify any changes in their use of community services resulting from patients' attendance at CREST. The phase two data collection design is summarised in Figure 6.5. This multi-method approach (Challis and Darton, 1990; Guba and Lincoln, 1981; Polit and Hungler, 1991; Treece and Treece, 1982) was selected to establish an accurate representation of CREST. The tools and methods used are described in Sections 6.6 to 6.8.

TIME FRAME WITHIN 18 MONTHS OF DATA COLLECTION PERIOD	**METHOD OF COLLECTION**	**PURPOSE OF DATA COLLECTION**
First year of operation	**CREST management meetings**	To identify changes in operational policy and nursing standards (structure and process)
At the end of 18 months	**Retrospective review of patients' nursing notes**	a)To identify whether the nursing framework for practice was used to assess, plan implement and evaluate care (process) b)To identify patient patterns of attendance and use of other services (process) c) To identify patient outcome (outcome)
Three periods in first 18 months	**Non participation observation of nursing staffs' activity**	To identify nursing activity (process)
Three periods in first 18 months	**Non participation observation of patients' activity**	To identify patient activity (outcome)
First year of their relative's /friend's attendance at CREST	**Interviews of carers and Crichton Visual Analogue Scale (two sub-scales)**	a) To identify effects of patient attendance at CREST on carers (outcome) b) To identify change in use of community services as a result of patient attendance at CREST (outcome)
First year of patients' attendance at CREST	**Crichton Visual Analogue Rating scales of patients by carers and nurses**	To assess patients' behavioural dependency over time (outcome)

Figure 6.5 Phase two data collection design

6.6 Non-participant observation

6.6.1 Activity codes: nursing staff

Nursing staff were observed in order to identify their activity while working at CREST. The problem of defining and describing the behaviours which would be included on the observation schedules for nursing staff activity was difficult to resolve (Macilwaine, 1983). Clearly, the nursing behaviours observed should be related to the framework for nursing practice and aims of nursing care (Macilwaine, 1983; St Ledger et al, 1992). It was anticipated that this approach would assist in identifying relationships between nursing activity (process) and patient and carer outcomes. A list of expected activities to be undertaken by nurses in CREST would was compiled. It contained two sections, non-clinical and clinical activity (Figures 6.6 and 6.7). The non-clinical activity code list was devised to measure how much time nursing staff spent in non-clinical work. Seven categories were identified (Figure 6.6).

The clinical list (Figure 6.7) reflected the framework for nursing practice, which stated that an aim of nursing at CREST would be to maintain or increase patients' independence, while ensuring patient comfort. The nurse activity code list included categories for assisting patients in fulfilling activities of living and encouraging patients in self care. The remaining categories in the clinical activity list were selected because they reflected CREST's nursing standards and the type of activity nurses undertake when caring for people who suffer from dementia (Bartol, 1970; Bergman, 1986; Lindeman et al, 1991; Norman, 1989, 1991; Raphael and Mandeville, 1979; Watkins, 1987a). Reviewing individual patients' nursing needs and clinical reporting were considered clinical activities. CREST had been specifically designed to encourage communication between nursing staff and carers, therefore three categories concerning this factor were included in the clinical code list.

NON-CLINICAL ACTIVITY CODE	
CODE	**ACTIVITY**
26	Time with other health care workers - liaising/communicating
27	Domestic work/bedstripping/making
28	Nursing - staff interaction including teaching/counselling
29	Reading/studying time
30	Researching data collection
31	Personal time (as distinct from official breaks)
32	Administration duties/other

<u>Figure 6.6 Non Clinical Nursing Activity Code</u>

DESCRIPTION OF ACTIVITY NURSE CLINICAL ACTIVITY CODE	
CODE	**ACTIVITY**
1	Social conversation
2	Purposeful therapeutic interaction
3	Giving instructions/information
4	Conducting individual behavioural programme
5	Delivering or preparing physical treatment/ test in day area/medication
6	Assisting with dressing/undressing
7	Assisting with eating
8	Assisting with hygiene
9	Assisting with toileting
10	Assisting with preparation for sleeping
11	Assisting with mobility
12	Observation of patients
13	Recreation with patient - individual
14	Recreation with patients - group
15	Conducting formal reality orientation group
16	Encouraging self care
17	Collecting patients from home (D) Driving
18	Taking patients home (D) Driving
19	Communicating with patient's relatives/friends at CREST
20	Communicating with patient's relatives/friends in their own home
21	Reviewing individual patient's nursing needs/care plans
22	Receiving, recording and giving clinical report verbal/written
23	Monitoring patient's sleep pattern
24	Communicating with patients' relatives by telephone
25	Other

Figure 6.7 Nursing Clinical Activity Code

6.6.2 Activity codes: patients

Patients were observed in order to identify how they spent their time when travelling to, from and at CREST. An activity code list was devised (Figure 6.8). In a similar manner to the nursing code list consideration was given to the type of nursing help patients with dementia could be expected to require. In addition, categories for time patients spent alone and interacting with other patients were devised.

AD	Assistance with dressing/undressing
AE	Assistance with eating
AH	Assistance with hygiene
AM	Assistance with mobility
AT	Assistance with toileting
AS	Assistance with preparation for sleeping
BP	Behavioural problem, i.e. shouting
SC	Self contained behaviour
I	Independent behaviours eg dressing/eating/drinking
IB	Individual behavioural programme being conducted
IN	Interacting with nurse
IP	Interacting with other patients
NESC	Nurse encouraging self care
NR	Recreation with nurse
PR	Recreation/interaction with other patients
ROG	Reality orientation group
RPC	Receives physical care/check, i.e. wound/pressure
S	Sleeping

Figure 6.8 Patient Activity Code

6.6.3 Pilot study: non-participant observation

The aims of the pilot study were to examine the feasibility of conducting non-participant observation of CREST nursing staff and patients using the activity code schedules. It was intended to observe two nurses at ten minute intervals for one night from 7 p.m. when staff commenced duty until completion of the night's work, when they returned the ambulance after all patients had been taken home. Similarly two patients would be observed at ten minute intervals from the time they were collected by CREST staff until they returned home the following day. The pilot study was carried out in January 1989, the month that CREST opened. The author conducted the non-participant observation and coded nursing staff and patient activity every ten minutes throughout the night.

Difficulty was experienced when attempting to differentiate the content of nursing staffs' interaction with patients in terms of therapeutic interaction, encouraging self care and giving information. In reality, when nursing staff were encouraging self care they were giving information, and motivated patients by encouraging them. The three categories were combined as one activity, therapeutic interaction including encouraging self care; otherwise the nursing staff activity code list was found to be appropriate.

Two areas of difficulty were experienced with coding patient activity. It was impossible to judge whether patients were actively disengaged or reading/watching television independently. Similar difficulty was experienced when patients were travelling in the ambulance. When a patient was sitting and looking out of the window, it was not possible to judge this behaviour accurately as either travelling or being disengaged. To overcome this problem the patient activity code schedule was altered (Figure 6.8). Three codes were removed (disengaged, reading/watching television and travelling) and a new code, self contained behaviour, was added.

The pilot study indicated that because nursing staff worked various shifts, some nurses would be observed for 12 hours during one night while others on a twilight shift or early morning shift would be observed for only three to four hours.

6.6.4 The main study: non-participant observation

Data were collected during the first 18 months of CREST's operation in order to identify and compare nurse and patient activity during three thee month periods (Figure 6.9). Non-participant observation was conducted by the author for one night per month with two nurses and two patients being observed at ten minute intervals. The patient and nurse activity codes adapted from those listed in Figure 6.6, 6.7 and 6.8 were used to categorise and record activity. It was decided to observe the two nursing staff who went out with the ambulance at 7 p.m. and when one had completed a shift and observe another member until completion of his/her shift. This allowed observation of up to five nursing staff of different grades during any one night. The length of time that individual nurses were observed depended on the shifts they worked and varied between 1 hour 40 minutes and 10 hours 10 minutes on any one night of observation. Each patient studied was observed for 10 to 13 hours during any one night. The duration of observation was dependent on the time of individual patient collection and return home. The time spent by patients in the ambulance travelling to CREST and returning home was measured and recorded at the time of observation.

MONTH OF CREST OPERATION		DATA COLLECTION PERIOD
Month 1	January 1989	Pilot Study
Month 2	February 1989	
Month 3	March 1989	Period 1
Month 4	April 1989	
Month 9	September 1989	
Month 10	October 1989	Period 2
Month 11	November 1989	
Month 16	April 1990	
Month 17	May 1990	Period 3
Month 18	June 1990	

Figure 6.9 Nursing staff and patient activity data collection periods

Nursing staff were informed that their behaviour was being observed but were unaware of the activity codes. The non-participant observer role was also explained to patients and carers. They were told that the observer was a nurse and that her role at CREST was to identify what actually happened during the night. It was explained to patients and carers that the author would be observing patients when they were being collected, returned home and while at CREST. The observer carried an A4 pad with coding sheets and pencils, sitting as unobtrusively as possible. When the nurses and patients being observed were outside her vision or hearing she moved to a position where it was possible to observe their behaviour and hear the content of their conversations. This meant that she sometimes had to follow patients into the bathroom or sit with them at a table when they were eating. When nursing staff were involved in paperwork the observer asked nurses what they were doing in order to code their activity accurately.

Observed activities were coded and recorded by the author at the time of observation. The judgements made concerning how to code patients' behaviour were based on the author's knowledge of and experience in nursing elderly people suffering from dementia. Her experience as a ward sister, nursing officer and tutor in mental health care influenced the judgements made when categorising nursing behaviour. It was essential to hear the content of nurse conversation with patients to make decisions when coding and consequently it was often necessary for the observer to stand or sit in close proximity to patients and nurses in intimate situations. An example would be when a nurse was assisting a patient using the toilet. For this reason it was felt inappropriate to have more than one observer. Similar approaches to non-participant observation have been taken by nurses undertaking research in mental health care for the same reason (Altschul, 1972; Towell, 1975).

6.6.5 Analysis of data: non-participant observation

Nursing staff took excessive personal break time when being observed. The time they spent in these unofficial breaks was omitted from the nursing staff activity analysis. The length of observation of each grade of nursing staff for each period was calculated. The percentage of time spent by each grade on clinical and non-clinical activity in each period and on each activity was calculated. The data were also examined to determine nursing staffs' peak workload periods.

The total duration of patient observation during each of the three periods (Figure 6.9) was analysed separately. The percentage of time spent by each group of patients in each activity listed in the observation schedule was then calculated for each period. The data were also examined to establish whether the results of this breakdown were representative of the sample observed, or whether particular behaviours could be attributed to individual patients. The data collected on patients' travelling times were analysed to identify the minimum and maximum lengths of time spent travelling.

6.7 Measurement of patient and carer outcomes

6.7.1 Crichton Visual Analogue Scale

The Crichton Visual Analogue Scale (Morrison, 1983) was used to measure patients' ability to conduct activities of living and the extent to which they displayed behavioural problems associated with dementia. The scale has ten patient orientated categories; six relate to activities of living (mobility, conversation, feeding, dressing, sleeping and continence) and four to behavioural problems (confusion, difficult, restlessness and mood) (Figure 6.10). The scale also has two categories to enable carers to self rate their perceived ability to cope with and their anxiety about their relative or friend who suffers from dementia (Figure 6.10). The Clifton Assessment Procedures for the Elderly (CAPE) Behaviour Rating Scale which is a tool for measuring patients' behaviour, was considered for this study (Pattie and Gilleard, 1979). It was rejected in favour of the Crichton Visual Analogue Scale which included carer rating scales, since it was proposed to study the effects of CREST on both carers and patients.

The Crichton Visual Analogue Scale was devised by Morrison (1983) for two purposes:

a) to enable carers to rate patients' dependency levels
b) to measure change in patients' behaviour over time.

The tool has satisfactory test/re-test reliability when used by carers and qualified mental health nurses (Morrison, 1983). Validity has been demonstrated by comparing patients' scores in different clinical areas. Patients whose clinical condition was clearly worse than others were rated significantly higher on the scale by both carers and nurses (Morrison, 1983). A significant positive correlation between the Crichton Visual Analogue Scale and the Psychogeriatric Dependency Rating Scale (Wilkinson and Graham-White, 1980) was found when ratings of in-patients and day patients were conducted independently by qualified mental health nurses and carers using the two scales (Watkins, 1987a). The tool has been found to give reliable and valid information concerning assessment of patients' behaviour (Morrison 1983; Watkins, 1987a).

	<- 10cm ->	
Gets about without help	__________	Confined to bed or chair
Never confused	__________	Completely lost
Helpful	__________	Very difficult
Can hold a conversation	__________	Does not make any sense
Able to feed themselves without help	__________	Needs spoon feeding
Able to dress themselves without help	__________	Needs to be dressed
Sleeps soundly at night without sleeping pills	__________	Never sleeps a wink
Does not wet at all	__________	Seldom dry
Seldom restless	__________	Never sits still
Mood seldom changes	__________	Very moody

Relatives only

I am coping well with my relative	__________	I am completely unable to cope
I am not at all anxious about my relative	__________	I am extremely anxious

Figure 6.10 Crichton Visual Analogue Scale for the assessment of behaviour in the elderly

The framework for nursing practice (Figure 6.3) was orientated towards promoting patients' independence in their activities of living and identifying and trying to alleviate the patient behaviours which caused carers most distress. In addition, an aim of the service was to provide relief to carers by working in partnership with them to deliver care to patients. The behavioural patterns listed in the Crichton Visual Analogue Scale were therefore considered appropriate for measuring outcomes of care.

The Crichton Visual Analogue Scale was not piloted in this project as its reliability and validity when used to measure patient dependency had been demonstrated previously (Morrison, 1983; Watkins, 1987a).

6.7.2 The main study: Crichton Visual Analogue Scale

Patient and carer outcomes were measured using the Crichton Visual Analogue Scale at four separate times over each patient's first year of attendance at CREST. The first measure occurred within one week of each patient's first attendance at CREST (Time A); subsequent measures were taken as follows:

Assessment	Time after Initial Attendance
Time B	6 weeks
Time C	12 weeks
Time D	6 months

Patients' primary nurses and carers independently completed a rating scale for each patient at each of these times. The purpose of the two independent ratings was twofold:

a) to increase the validity of the findings by gaining both the professional nurses' and informal carers' perceptions of the patients;

b) to identify whether any difference between ratings conducted by carers and nurses changed over time.

The assessments were conducted at these intervals for the following reasons. First, previous work had demonstrated that in-patients suffering from dementia responded to nursing care in that they changed in their ability to conduct activities of daily living within the first six weeks of receiving care (Watkins, 1987a). Secondly, it was anticipated that attendance at CREST might in the first instance increase patients' behavioural problems due to a change in their normal routine and environment. Alzheimer's disease and multi-infarct dementia are both progressive illnesses (Chapter 2). CREST patients' levels of dependence could be expected to increase over time. Conducting measurements at the intervals selected would produce data which could be interpreted in relation to these factors.

Either the charge nurse or author gave a simple verbal explanation on how to use the Crichton Visual Analogue Scale to each primary nurse, all of whom were registered mental nurses. Primary nurses were then asked to assess each patient for whom they were responsible using the Crichton Visual Analogue Scale at Times A, B, C and D. In some instances patients were absent from CREST when an assessment was due, in which no rating was conducted by nurses. Carers were interviewed at Times A, B, C and D (Section 6.6). At interview they were asked to assess their relative or friend using the Crichton Visual Analogue Scale and to complete the two sub-scales relating to themselves. The interviewer gave a simple verbal explanation to carers on how to complete the scale.

Carers were interviewed, whenever feasible, when CREST patients were ill at home or temporarily receiving residential or in-patient respite care. Therefore carers sometimes completed the Crichton Visual Analogue Scale assessments for patients when primary nurses did not.

6.7.3 Analysis of Crichton Visual Analogue Scale: initial ratings conducted by nurses

The Crichton Visual Analogue Scale ratings of patients completed by primary nurses at Time A were analysed to identify the degree of behavioural dependence of the patient group as perceived by the nurses (n=31). The median patient rating and range were calculated for the total group. The same calculation was conducted independently for male and female patient groups. Individual patients' ratings as recorded on each patient sub-scale of the Crichton Scale were then calculated within a ten-point band. The first band was calculated between 0 and 10 having an eleven-point range, the remaining bands had 10-point ranges (11-20, 21-30 up to the tenth range, 91-100). The number of patients who were rated within each band was then identified.

Scores on each sub-scale of the Crichton Visual Analogue Scale were calculated; reading the scale from left to right, each millimetre was marked off in whole units from 0-100 as described by Morrison (1983). To maximise reliability the author used the same perspex ruler to read scores for each sub-scale throughout the period of analysis.

Paired sets of data collected at Times A, B, C and D were compared (Figure 6.11).

Nurses' Crichton Visual Analogue Scale ratings of patients

Time A with Time B
Time A with Time C
Time A with Time D
Time B with Time C
Time B with Time D
Time C with Time D

Carers' Crichton Visual Analogue Scale ratings of patients

Time A with Time B
Time A with Time C
Time A with Time D
Time B with Time C
Time B with Time D
Time C with Time D

Nurses' and carers' Crichton Visual Analogue Scale ratings of patients

Time A nurses with Time A carers
Time B nurses with Time B carers
Time C nurses with Time C carers
Time D nurses with Time D carers

Carers' Crichton Visual Analogue Scale self ratings

Time A with Time B
Time A with Time C
Time A with Time D
Time B with Time C
Time B with Time D
Time C with Time D

Figure 6.11 The paired sets of data collected using the Crichton Visual Analogue Scale

Nurses' and carers' ratings of patient dependence and carers' self ratings on the visual analogue scale were analysed using non-parametric statistical tests, as the sample sizes were small and it could not be assumed that the data were normally distributed. Total Crichton Visual Analogue Scale scores were analysed for each individual patient to compare ratings over time. A more detailed breakdown was conducted with the ten sub-scales of the Crichton Scale scores analysed individually. Wilcoxon Matched-Pairs Signed Ranks Test was used to analyse these data. Patient ratings at Time A were analysed and compared with patient outcome using Kruskal Wallis analysis of variance of ranks. Two-tailed tests were used and the probability of results occurring by chance was put at less than 1 in 20 ($p<0.05$). The SPSSX statistical package was used for the statistical analysis (Norusis, 1985).

Spearman's rho was used to calculate the correlation coefficient between carers' and nurses' ratings of patients at Times A, B, C and D.

6.7.4 The timing structure and purpose of carer interviews

Carers were interviewed at Times A, B, C and D when they completed assessments using the Crichton Visual Analogue Scale as described in Section 6.7. Carers were asked to complete a consent form to indicate their agreement to enter the study (Appendix 6.4). One reason for interviewing carers was to gather information about the effects on them of their relative's /friend's attendance at CREST. In addition, information concerning the community services that carers and patients received was required.

A semi-structured interview schedule was prepared containing three questions concerning the feelings experienced by carers about their relative or friend's attendance at CREST, the effects of attendance on carers' lifestyle and use of community services (Appendix 6.5).

6.7.5 Preparing the interviewers and conducting a pilot study

Two senior nurses, with considerable experience in working with patients who suffered from dementia, were appointed to interview carers. The author explained to them the purpose of the interview them and stressed the importance of following the proposed schedule to enhance inter-rater reliability. It was recommended that they took no more than 45 minutes for each interview.

Each interviewer conducted pilot interviews with six carers of patients who attended the day hospital. The questions outlined in Section 6.8.1 were used with the words "day hospital" being substituted for "night hospital". The interviewers recorded carers' responses on the three-page interview schedule at the time of interview. They were then asked to read back the written data to the carer who had been interviewed. The carers were asked whether the representation of their answers was correct and if they wished to add any further information, thus increasing the potential for data credibility (Guba and Lincoln, 1981).

The author discreetly attended the pilot interviews and collected written information in the same way as each interviewer. After each pilot interview the interviewer and author's interview schedules were then compared. Consistency in the content of data collected by each interviewer and the author was established by the time each interviewer conducted his/her fifth interview. The information collected was considered appropriate for the purposes identified in Section 6.7.1.

Interviewers asked carers to complete the Crichton Visual Analogue Scales before the interview. No carer in the pilot study appeared to have difficulty in completing the scales, following explanation from the interviewer.

6.7.6 The main study: interviews of carers

Interviewers were informed of each patient's admission and how to contact carers to arrange interviews. An appointment for the interview was made within one week of the patient's admission to CREST.

At the first interview carers were told the purpose of the interview and it was explained that they were under no compulsion to be involved. They were assured that their relative or friend's attendance at CREST was not dependent on the carer agreeing to take part. No carer refused to be interviewed.

Interviews usually took place in carers' homes, although occasionally at CREST. Carers were interviewed at Times A, B, C and D by one of the two interviewers. In the majority of cases they re-interviewed carers they had previously seen.

Interviews were conducted according to the method described in Section 6.7.5 without the author being present.

6.7.7 Analysis of interviews

Data collected on the Crichton Visual Analogue Scale were analysed as described in Section 6.7.3. The information collected from question 1 of the interview (concerning carers' feelings about their relative/friend's attendance at CREST) were analysed at the manifest level (Fox, 1982). Analysing material at the manifest level involves classifying what the respondent actually said without interpreting the response, thus avoiding misinterpretation. The transcripts were analysed for common and unique themes of carers' responses to this question. Themes expressed by carers were related to biographical grouping in order to identify possible emergent patterns (Appendix 6.6).

Question 2 was analysed to identify the number of carers who reported changes to their day to day life as a result of their relative's /friend's attendance at CREST. The second section of this question was analysed in the same way as Question 1.

Question 3 was analysed for the number of patients and carers who had been in receipt of particular services and the changes that carers reported.

The results obtained from all three questions were then considered with reference to the literature reviewed in Chapter 3, concerning carers of elderly people who suffer from dementia.

6.8 Review of nursing notes

6.8.1 Purpose and structure of note review

There were three reasons for reviewing nursing notes: first, to collect biographical and numerical data on the number of patients referred to, accepted by and who attending CREST. A simple referral form was designed for this purpose and used in the main study

(Appendix 6.7). Secondly, the pattern of patients' attendance at CREST was of particular interest. The first patient to be admitted went into in-patient respite care for two weeks after his first month at CREST. He was discharged from CREST at that time but was subsequently re-admitted. It became clear that many CREST patients could require periods of hospital care for treatment or residential respite care. It was therefore decided that patients would continue to be registered at CREST when they were receiving short term care of this kind if it was likely that they would return. Information was collected concerning attendance patterns and discharge under the following headings:

a) Use of in-patient care
b) Use of respite care
c) Use of day services
d) Numbers of attendance per week
e) Number of weeks on CREST register
f) Patient outcome on discharge

The third reason for reviewing nursing notes was to identify whether the nursing framework for practice was used to assess, plan, implement and evaluate care. An assessment schedule was designed for the author to use when reviewing notes (Appendix 6.8). A more detailed review of four patients' nursing notes was made with the aim of collecting data which would illustrate whether the framework was used to plan care which reflected carers' wishes and promoted patient independence and choice.

6.8.2 The main study: review of nursing notes

No pilot study was conducted to test the forms for collecting information concerning patient referral and attendance at CREST. The CREST charge nurse was responsible for completing a referral form for each person who was assessed for suitability to attend CREST, each patient's primary nurse completed a CREST attendance data collection sheet for the period of the patient's registration. The data on each sheet included the number of nights' attended per week and the reason for any non-attendance. Thus, if a patient was ill at home, an in-patient for treatment, or receiving respite care, this was recorded. When patients were in regular receipt of day care this was also recorded. Each night the number of patients attending CREST was recorded by either the charge nurse or a primary nurse.

The author reviewed patients' notes schedules six months after completion of the main 18-month data collection period. This interval ensured that sufficient material was available for review.

6.8.3 Analysis of nursing notes

The number of people referred and by whom were counted. The number of places offered was counted and when an offer was refused the reasons for this were identified when relevant information was available.

The data were analysed to identify the residential and day facilities used by CREST patients. The reasons for a patient's discharge from CREST were then cross-tabulated to investigate any association between attendance at certain facilities and particular outcomes, for example, whether patients who used in-patient respite care were more likely to be discharged to residential care from CREST than those who did not use the service. Similarly, any association between patient outcome on discharge from CREST and their diagnosis and familial relationships between patients and their carers was investigated for the total patient sample. When sample sizes were sufficient the Fisher's Exact Test

was used to test the significance of the association.

The number of care plans which followed the nursing framework for care and the care planning standard were summed. The assessment schedule had been devised with three catAs, "yes", "no" and "not applicable". In addition, examples of statements from care plans which the author interpreted as indicating the use of the nursing framework were selected to illustrate its application in practice.

6.9 Summary and final analysis

Evaluation research should follow a systematic approach to information collection and involve measuring the subject of investigation against pre-stated goals (Cronbach et al, 1982; Guba and Lincoln, 1981; Suchman, 1967). In addition, measurements of the degree of change which takes place in the structure, processes and outcomes of the service should be conducted (Bernstein and Freeman, 1975; St Ledger et al, 1992; Suchman, 1967). The multi-method approach to evaluating CREST was taken to enable systematic data collection and enhance rigour (Guba and Lincoln, 1981). It was anticipated that the information collected would be appropriate for comparing CREST against its stated aims, as defined in Section 6.2.

The data collection plan was constructed so that the research might proceed in an orderly pattern. Phase 1 involved formulating the operational policy (structure) and nursing standards (process) for CREST. In Phase 2 the data were collected and analysed. Throughout both phases cognitive reflection and analysis occurred. Information concerning the process of care at CREST was collected by non-participant observation of nursing staff and patient activity. The review of patients' care plans provided information about application of the nursing framework.

Patient and carer outcomes were measured at periods of time over the first six months of patients' attendance at CREST using the Crichton Visual Analogue Scale. Carers were also interviewed to identify the effects of CREST on themselves and their use of other community services.

Data on each method were initially analysed independently, following which possible relationships between structure, process and outcome were investigated. The evaluator reflected on the total data collected and combined them to provide a comprehensive case study of CREST and made judgements concerning relationships between the service's structure, processes and outcomes (Cronbach et al, 1982; Suchman, 1967; Walker, 1980). This involved a process of analysing that tested out the "qualities" of the properties of CREST to gain a fuller understanding. The cognitive process was central to this research analysis stage (Glaser and Strauss, 1967).

It has been suggested that in order to be most useful data should be maintained at a level of complexity that is neither too simple nor too complex (Guba and Lincoln, 1981; Treece and Treece, 1982; Polit and Hungler, 1991). A balance was achieved that retained the complexity of the service being evaluated but that was not so complex as to make analysis within and between methods unattainable.

The reflective process has been described in a sequential way, inferring that individual data sets were collected prior to any cognitive analysis. In fact, data collection and analysis were closely integrated. When conducting non-participant observation the author reflected on the reasons for certain nursing staff behaviours, and the type of nursing organisation at CREST. These reflections were of particular value when considering potential relationships between nursing processes and patient outcome.

One way of measuring the success of an evaluation is to identify whether the results have influenced the evaluation commissioners' decision making processes concerning the programme investigated (Stronbach, 1986; Suchman, 1967; Walker, 1980; Weiss, 1986, 1972). The final stage of the research process occurred when the author returned to the unit to learn about the decisions that had been made concerning the future provision of CREST.

The next chapter reports the results of data collected during Phase 1, from attendance at CREST management meetings, observation of nursing activity and review of patients' individual care plans.

CHAPTER 7

OPERATIONAL POLICIES AND NURSING ACTIVITY

7.1 Introduction

This chapter describes the final preparation of staff and the promotion of the CREST service prior to its opening. The changes which were made to the operational policy and the nursing standards within the first year of CREST's operation to meet the requirements of patients and their carers are detailed.

The results from the observation of nursing activity are presented and described. In addition the data collected from reviewing patients' individual care plans are presented. The extent to which nursing standards were adhered is examined. Indicators of quality of nursing care in terms of nursing staff activity and the content of care plans are discussed. Evaluation of carer and patient outcomes is presented in Chapters 8 and 9. The final analysis of the quality of nursing care is presented in Chapter 10 when relationships between structure, process and outcome at CREST are considered.

7.1.1 Nursing preparation

The charge nurse appointed to CREST worked with the sister in the day hospital for a week so that they would understand each others' views about sharing the building. During this time it was agreed that CREST patients and staff would have access to the art and recreational therapy rooms at night. It was decided that the physiotherapy room would not be used by CREST patients but that this could be reviewed at a later date. The day hospital had several patient amenities, donated by grateful patients and the League of Friends, including hairdryers, televisions and board-games. The day hospital sister generously agreed to share these items. In return it was agreed that CREST would purchase a video cassette recorder which could be used to show both reminiscence tapes and old films to patients. During the first year of CREST small problems concerning the sharing of the building occurred; however, as both senior nurses were committed to working together over time, these were all resolved.

The literature reviewed in Chapter 5 illustrates the value of continuing education for nursing staff in enhancing the delivery of quality care. All staff were given a two-week orientation period. The purpose of the orientation was twofold; to ensure that all nursing staff were aware of the standards for their practice, and to update their knowledge of the type of patients and carers to be served by CREST. During this time staff were able to prepare and negotiate with managers the way in which they would work. All nursing staff attended sessions concerning CREST's operational policy, nursing framework and standards. The author introduced the nursing framework and two days were spent exploring, with clinical vignettes, how it might be applied. Subsequent sessions were led by the charge nurse. They included updating nurses' knowledge about dementia and problems faced by carers, and explaining the nursing standards expected.

During the orientation period the first CREST patient was referred and accepted. This patient's wife asked whether attendance could be started rapidly. All staff decided that they would like to start CREST to meet this carer's wishes. They used this admission to identify and rectify minor operational problems before the official starting date the following week. For example, the staff identified the need for Parker-Knoll recliner chairs, because this first client needed to sit in a recumbent position due to his breathing difficulties. Chairs were transferred from the main hospital and the patient was able to sleep comfortably. He did, in fact, sleep in a reclining chair at home, so that the lack of a hospital bed at CREST was not considered a problem at this point.

Clinical nursing staff directed and altered their own orientation programme in response to the needs of the first patient. This illustrates the potential of a management structure which encourages autonomy and innovation at a clinical level (Fain, 1985; Murphy, 1986b).

7.1.2 Promoting the service

Marketing involves preparing a product which meets customers' requirements and informing potential customers of the product's existence. It was important that staff employed in primary health care teams, social service departments and the community and mental health units of the health authority were informed that a night nursing service was being developed, so that they could refer appropriate patients to it. The mental health unit's press and public relations officer was asked to assist in preparing information to advertise CREST's existence.

The acronym "CREST" stood for: Care and Respite for Elderly people with Support and Treatment. The press department produced a logo representing the new moon with the "C" and "rest" within the "C" - CREST . They suggested that this logo could be interpreted in two ways - the intention explicit in the title, and as "carers rest". The logo was accepted by the project team.

The press department produced posters for general practitioners' surgeries and health care clinics advertising the service. A strategy for marketing the service was then agreed, which involved targeting the groups referred to above and local carer groups. A letter from the charge nurse enclosing a poster was sent to 19 general practitioners' surgeries within the health authority, stating that the charge nurse would telephone the surgery within a fortnight to answer any questions about CREST and to make an appointment to visit and speak to staff, if so desired. Eight of the surgeries asked her to visit. Four sector social work teams were also sent information and two teams asked the charge nurse to visit to explain the service in more detail. By far the greatest interest in the service was expressed by the district nurses. All community nursing teams were visited. Subsequently, referral forms and CREST information packs were sent out to all the agencies originally targeted, together with a letter expressing the charge nurse's thanks for the opportunity to speak to the teams she had visited.

Eleven groups associated with carers of people with dementia known to the project team were approached in a similar way. The charge nurse was invited to speak to six of those groups. Most of those attending the groups supported the idea of CREST, although several also said that they would be worried about sending their relative/friend out at night. It quickly became apparent that this was something the charge nurse needed to consider when trying to influence the attitudes of carers. The literature reviewed in Chapters 3 and 4 indicates that many carers are reluctant to use statutory services and that sometimes they will refuse help until a crisis occurs. The charge nurse was aware of these issues and recognised that she would need to repeat her visits to carer groups to encourage acceptance of CREST. It was hoped that once CREST had some patients using the service its benefits would become clear to carers. All staff recognised the importance of working with carers to ensure that patients' programmes were developed in such a way that carers' opinions were considered. This, it was believed, would encourage patients to continue to attend.

The initiation of CREST was seen as an opportunity to advertise the innovative nature of the mental health service. The general manager approached Rabbi Julia Neuberger who agreed to open the service. Formal invitations were sent to 150 people, including representatives from the press, local dignitaries, members of the health authority, local general practitioners and representatives from social services, community nursing teams and carer groups. Seventy people attended CREST's official launch on 10 January, 1989. Guests were encouraged to ask CREST nursing staff, who wore bright identification labels, about the service. Two hundred CREST information packs, which included referral forms, and ten press packs were made available.

Following the launch, both local newspapers reported the event and one indicated how carers could refer friends or relatives to CREST. It was recognised that it would be necessary to continue to publicise the service using personal contact with community health and social care teams.

7.2 Alterations to operational policy and nursing standards: the first year

7.2.1 CREST management meetings

The CREST charge nurse initially held meetings with her staff on a weekly basis and, after two months, every two weeks. One purpose of these meetings was to define any alterations that should be made to operational policy or the nursing standards. The nursing team was encouraged to use the quality assurance principles outlined in Chapter 5, Section 5.1 to reflect on the new service. Nursing staff encouraged both carers and patients to make suggestions concerning possible changes to best meet their requirements. The factors suggested by carers and patients, as well as ideas put forward by nursing staff, were then considered at CREST meetings. Suggestions for change to policy were then discussed with the community manager responsible for CREST. When a system for change had been agreed and devised by the CREST team it was presented to the management team for discussion and authorisation.

The CREST management team met every two months for the first year of operation; membership comprised the project team (Chapter 6, Section 6.2). The chairman, the director of nursing services, was able to approve changes to CREST without calling a meeting if a rapid change was desirable. It was intended that the management team would support CREST staff and respond to requests for alterations in the service quickly.

In addition to incremental alterations there were three fundamental changes to operational policy during the first year. These included the times at which patients were collected in the evening, the grade mix of staff and the linking of some patients' attendance at day care with their nights at CREST. A medicine policy was introduced and included in the nursing standards (Appendix 7.1).

A major managerial reorganisation occurred as a result of the amalgamation of the community and mental health units. At that time it became appropriate for CREST to be managed within the elderly care team rather than the community psychiatric nursing team.

7.2.2 Collection times

Collecting patients from their own homes was time consuming, partly because of the desire to build relationships between primary nurses and patients' carers, and often information was exchanged between nurses and carers at this time. When the ambulance arrived to collect patients they were sometimesthought to be too unwell to attend CREST; in these circumstances nurses offered to help carers put the patient to bed at home. While these actions reflected the philosophy of the service, they caused delay to subsequent patients. Therefore, following consultation with carers, after 10 months of operation it was decided to start the round an hour earlier at 6.00 p.m. This extra hour ensured that no patient was collected after 9.00 p.m. other than in exceptional circumstances. It also gave nurses time to talk with carers.

7.2.3 Linking CREST attendance with day care

Some patients who were attending CREST also went to a day hospital or day centre for one or two days a week. The carers of these patients asked if it would be possible for their relatives to be transported directly from CREST to the day care centre rather than being taken home by the CREST ambulance and collected by another to go to their day care centre. Carers wanted a 20 hour break once or twice a week with their relative combining a night at CREST with day care the following day. The centres that these patients were attending were using the London Ambulance Transport Service. The local London Ambulance Service manager said that their ambulances could only take patients home from day care if they had delivered them there from home in the morning. His reasons were that the rules would not allow a patient to be picked up from one address (CREST) and taken to another (home) and the London Ambulance Service could not guarantee a specific pick-up time. It was, therefore, decided that until a more suitable arrangement could be made the CREST ambulance would be used to take patients to day care, and the psychogeriatric day hospital ambulance would be used to collect CREST patients from their day care and return them home. Within two months the London Ambulance Service agreed to pick up CREST patients from their day care and take them home.

7.2.4 Grade mix

During the first year of operation the change in collection time of patients, coupled with the fact that the morning run was hampered by London traffic, meant that the CREST service had to be covered by staff from 6.00 p.m. to 9.30 a.m. The nursing assistant did not wish to extend her hours, so she agreed to drive the ambulance every morning and work from 6.00 a.m. to 10.30 a.m. four days a week. She could then take patients home and return the ambulance to the main hospital. The nursing staff agreed to do the evening driving, which required only a small increase in D grade overtime. One of the part time enrolled nurses wished to increase her hours to full time and was willing to take on prime responsibility for driving the ambulance in the absence of the nursing assistant. The willingness by all staff to overcome this problem illustrated their team cohesion and commitment to the service. These suggestions were accepted by the service managers.

During the first year of operation, two qualified members of staff resigned. The charge nurse chose to alter the staffing grade mix to stay within the budget rather than argue for additional resources; this decision was made because of the type of work involved with CREST. The duties of driving and housekeeping required additional nursing assistant hours. Two people were often required to assist patients with their activities of daily living which would, for example, involve lifting patients into the bath. The primary and associate nurses therefore required help from another member of staff to fulfil patients' needs, yet it was not necessary for the second person to be a qualified nurse. The associate nurse grade C posts were discontinued and the grade D primary nursing posts and grade A assistant posts were increased. Within a year the staffing was as follows:

G grade - 1 full time
E grade - 1 full time
D grade - 2.48 whole time equivalents
A grade - 1.48 whole time equivalents

The total cost of this grade mix reduced the nursing budget by approximately £10,000 per annum in comparison to the original grade mix. This money was used to employ agency nurses when nurses needed sick or maternity leave.

7.2.5 Additional nursing standard

The second patient who attended CREST was prescribed night sedation and anti-hypertensive medicines, which were given by his carer to the nurse in an envelope. The potential hazards of managing medicines in this way were immediately recognised by nursing staff. A safe medicine policy (Appendix 7.1) was devised and implemented. This was the only formal alteration to the nursing standards recorded within the first year of CREST's opening.

Alterations to the operational policy and the introduction of a medicine standard described above indicate the importance of encouraging clinical staff to identify strategies for resolving operational problems using a quality assurance framework. By monitoring and reflecting on the service with patients and their carers, the clinical nurses identified and implemented changes to the policy in order to enhance the quality of care.

7.3 Observation periods

7.3.1 Time and grade mix and times observed

The staff grade mix in CREST altered over the period in which nurse activity was observed primarily because of the extended hours of operation. Whenever possible, two nurses were observed over the same period. Each nurse's activity was observed at 10 minute intervals throughout their span of duty. Their observed behaviour was coded immediately as described in Chapter 6, Section 6.5.5. In total observation data were collected for the following periods:

Period 1	68 hours 50 minutes
Period 2	71 hours 50 minutes
Period 3	88 hours

During one night's observation in Period 1 taxis were used to transport patients; therefore, only one nurse's activity was observed for a 3 hour period. The increase in time observed between Periods 2 and 3 was due to the extended hours of operation.

All grades of staff were observed to take excess break time away from patients during the periods observed. In the first period 18 hours 10 minutes in excess breaks were taken over the three full nights observed. This time was fairly evenly distributed among the staff on full length shifts. It appeared that nurses were under-employed at the time that these observations were made and that they had agreed between themselves to cover for each other, leaving only one nurse on duty to monitor patients. Two or three patients were attending CREST at this time. This system worked well, in that the person taking a break was available locally and could be called upon when help was needed. Although staff were taking extended unofficial breaks they did not appear to be putting patients' safety at risk. At the time of recording the first period staff were offering a great deal of flexibility by responding to the need to try out different shifts in order to identify the best way of meeting the demands of an, as yet, untried service.

In Period 2 nurses were similarly observed to take excess break hours which totalled 13 hours, a reduction of one third in comparison with the previous period. An increase in the number of patients attending was also noted, with six present on one night's observation.

In Period 3, when between six and nine CREST patients attended, only 10 hours of nursing time was observed to be spent on unofficial breaks. On the nights when nine patients attended no unofficial breaks were taken. These findings suggest that the breaks were taken when the number of attenders at CREST was low and little nursing work was required once patients were sleeping or resting. When fewer than six patients attended CREST there did not appear to be a need for two members of nursing staff to be present between the hours of 1 a.m., by which time most patients had settled to rest, and 5 a.m., when some patients began to wake up and require nursing assistance (see Chapter 9). It was decided to omit these breaks when calculating nurses' activity because no further insights could be gained by including the data. Nursing activities (excluding unofficial breaks) were observed for variable lengths of time for each grade in the three periods (Table 7.1).

	GRADE	TIME		NUMBER OF OBSERVATIONS
		HOURS	MINUTES	
PERIOD 1	G grade	3	30	21
	E grade	5	20	32
	D grade	26	50	161
	C grade	13	20	80
	A grade	1	40	10
PERIOD 2	G grade	4	40	28
	E grade	10	10	61
	D grade	42	10	253
	A grade	1	50	11
PERIOD 3	G grade	8	40	52
	D grade	26	00	156
	A grade	43	20	260

Table 7.1 Nursing activity with patients: time observed for each grade (excluding unofficial breaks)

7.3.2 Clinical and non-clinical activity

The time spent by the nurses of different grades observed in clinical and non-clinical activity is presented in Table 7.2. Detailed results from non-participant observation are presented in Appendix 7.2.

	Period 1		Period 2		Period 3	
GRADE	Time observed	% of time	Time observed	% of time	Time observed	% of time
G - Clinical	3 h 30 m	38.1	4 h 40 m	50.0	8 h 40 m	67.3
- Non-Clinical		61.9		50.0		32.7
E - Clinical	5 h 20 m	68.8	10h 10 m	72.1	NOT OBSERVED	
- Non-Clinical		31.2		27.9		
D - Clinical	26h 50 m	68.3	42h 10 m	56.5	26 h	80.8
- Non-Clinical		31.7		43.5		19.2
C - Clinical	13h 20 m	67.5	NOT OBSERVED		NOT OBSERVED	
- Non-Clinical		32.5				
A - Clinical	1 h 40 m	90.0	1 h 50 m	72.7	43h 20 m	76.8
- Non-Clinical		10.0		27.3		24.2

Table 7.2 Time spent by staff in clinical and non-clinical activity

In the first period the primary and associate nurses (grades E, D and C) spent 67 - 69% of their time conducting clinical care. The G grade nurse only spent 38% of observed time in clinical care, but her job description clearly stated her managerial and research responsibilities, both of which accounted for the considerable time (62%) spent on non-clinical activity in the 3.5 hours for which she was observed. The G grade nurse was also involved in conducting initial clinical assessments in patients' homes which were not observed, thus underestimating the amount of time she spent in clinical activity. Allowing for these home visits, it is estimated that 50% of her working time was spent in clinical activity.

The nursing assistant was observed for 1 hour 40 minutes during the first period, on an evening shift. She spent 90% of her time in clinical contact with patients, 60% of which involved driving (Appendix 7.2). When driving she frequently talked to patients in the ambulance, and this was recorded as clinical time.

The grade C member of staff had been replaced by increases in grade D and A staff hours between the first and second observation periods. In the second period sampled the grade A nursing assistant was again only observed for a brief period, this time for 1 hour 50 minutes. Although she had become a full time employee she was on annual leave, except for one twilight shift (6.00 p.m. to 10.30 p.m.) during the second period sampled. As she was owed some time she left, by prior agreement, at 8.00 p.m. on the evening of the night immediately preceding her holiday. In the grade A's absence the nursing agency was unable to supply an alternative nursing assistant able to drive the ambulance. Therefore, CREST grade D nurses worked overtime so that two CREST nurses were always on duty. An agency staff nurse was employed for brief periods when a third nurse was required. It was decided to observe the permanent CREST staff rather than the agency nurse, so that comparisons across periods could be made.

In the second period the grade E primary nurse had maintained a similar level of clinical activity (72%) to the first period (69%) while the grade Ds had reduced their clinical activity from 68% to 57% compared with the first period. The decrease in grade D clinical time was attributed to their taking on activities such as housekeeping, which would have been conducted by the grade A assistant who was absent for most of the period sampled. This interpretation was reinforced in the third period, when grade D clinical activity rose to 80% of total work activity time.

The grade G charge nurse increased her clinical activity at night from 38% in the first period to 50% in the second and 67% in the third period observed. This alteration corresponded with resolution of the initial administrative problems. In addition, the research data collection had become more familiar to her, thus reducing non-clinical demands on her working time. In the period of the third sample the E grade nurse had resigned and the grade G had temporarily taken over the E grade's primary nursing responsibilities, thus increasing the clinical demands on her time. As the charge nurse was conducting all the initial assessments of people referred to CREST it was estimated that she was spending a minimum of 75% of her total working time (including day duty) in clinically orientated activities during the third period sampled.

In the third period the A grade posts were of increasing significance in CREST. The E grade post had been temporarily replaced by an A grade nursing assistant from an agency. This person had considerable experience of working with elderly people in an independent capacity, with both the social services and in the private sector. The other employee in this category had worked in CREST since its inception. She knew the patients attending and the way in which the service was organised. Each of the A grade employees worked a full 10 hour shift on two of the nights observed and shorter shifts on the other nights, resulting in 43 hours 20 minutes of their time being observed. They spent 77% of their time in clinically related activities.

Non-clinical work conducted by each grade varied (Appendix 7.2). Qualified nurses were involved with research data collection, administrative duties and teaching other staff. Domestic work, including bed stripping and making, was usually undertaken by the nursing assistants, although grade D nurses performed this when assistants were not available.

Patient activity at CREST (Chapter 8, Section 8.4) indicated that the increased time spent by qualified nurses in clinical activity between Periods 1 and 3 (Table 7.2) was related to more patients attending CREST rather than additional nursing time being spent with individual patients. The reduction in clinical activity of the two grade D nurses during the second period was related to the absence of grade A staff at that time. At Period 3, when two nursing assistants (grade A) were observed for full shifts, they spent a similar proportion of their time in clinical activity compared to qualified nurses (Table 7.2). Four types of clinical activity are examined in more detail to illustrate the scope of nursing work at CREST.

One indicator of individualised care is purposeful therapeutic interaction. This was recorded when nurses initiated actions which encouraged self-care and gave patients information or instruction so that they could perform self care and exercise choice; for example, with personal hygiene and diet. If a nurse asked a patient which cereal she would like for breakfast, specifying the variety on offer, and then encouraged the patient to prepare her own breakfast, this would be recorded as purposeful therapeutic interaction. If, however, a nurse said to a patient, "Your cornflakes are on the table and I've put the milk on them", this would have been recorded as "assistance with eating". The observer distinguished between the content and style of nurses' interactions at the time of observation and coded nursing activity based on her judgement.

In addition to purposeful therapeutic interaction, communication with carers was considered to be a specific indicator of individualised care. The proportion of time spent on these two activities is presented in Table 7.3. CREST staff communicated with carers when collecting and delivering patients home and when a carer brought a patient to CREST. Telephone calls between nurses and carers also occurred.

		THERAPEUTIC INTERACTION	**COMMUNICATION WITH CARERS**
Period 1	**Time Observed**	**% of time**	**% of time**
Grade G	3 h 30 m	4.8	9.5
Grade E	5 h 20 m	6.3	0.0
Grade D	26 h 50 m	9.3	5.5
Grade C	13 h 20 m	10.0	6.3
Grade A	1 h 40 m	10.0	0.0
Period 2			
Grade G	4 h 40 m	14.3	10.7
Grade E	10 h 10 m	9.8	13.1
Grade D	42 h 10 m	7.9	4.0
Grade A	1 h 50 m	0.0	0.0
Period 3			
Grade G	8 h 40 m	5.8	0.0
Grade D	26 h	7.7	1.9
Grade A	43 h 20 m	6.5	4.6

Table 7.3 Time spent by staff in purposeful therapeutic interaction with patients and communicating with carers

The charge nurse was observed going to patients' homes in the second period sampled, when she spent 11% of her time communicating with carers. In addition she communicated with carers when on day duty. This time was not observed. She reported that she undertook assessments of new referrals during the day and always involved carers in that process. She also arranged for carers to be visited by the patients' primary nurses approximately every six weeks. These visits were introduced between the second and third periods sampled, in an attempt to reduce the duration of the evening collection round of patients. Although she saw the need for nurses to interact with carers in the evening, the charge nurse believed that review with carers of patients' progress was best conducted at another time. During these visits primary nurses spent about an hour with carers, which enabled them to exchange information about patients and teach carers how to conduct personal care safely (e.g.

lifting on and off a commode). The reduction in time spent communicating with carers at night by qualified staff between periods 2 and 3 is marked (Table 7.3). Although this can, in part, be explained by the introduction of home meetings with carers, the increase in the time spent in this activity by the nursing assistant to 5% in the third sample suggests a change in the grade of staff liaising with carers when collecting and delivering patients home.

The way in which data were collected concerning staff interaction with carers did not distinguish between the content of the individual interactions. An additional note was made by the observer when collecting the information on interaction between nursing assistants and carers during the collection. Of the two nursing assistants observed it was the permanent member of staff who communicated with patients' relatives. She had come to know carers during the time that their relatives attended CREST, and not only talked with them about patients but asked carers how they were and about their social activities. The grade D nurses who accompanied the nursing assistant in the ambulance chatted less freely with carers. The grade D nurses spent only 2% of their time communicating with relatives at night during the third period observed. In one instance a nurse used a brief contact with a patient's carer to make an appointment to discuss the patient's care. The introduction of visits by primary nurses to carers outside CREST hours appears to have reduced the amount of time they spent interacting with carers when collecting patients from home and returning them the next morning.

Up to 38% of nurses' time was spent observing and monitoring patients' sleep (Table 7.4). The length of time spent monitoring sleep varied, according to the time that patients settled and whether or not they woke early in the morning. The time the nursing staff spent in clinically related activities other than monitoring sleep could only occur, of course, when patients were awake. Most patients slept for at least six hours when at CREST but woke frequently during the night (Chapter 8, Section 8.4.1). Therefore, the proportion of nursing time spent on purposeful therapeutic interaction with patients who were awake was in fact far higher than that reported in Table 7.3. It is estimated that when patients were awake, over 15% of nursing activity involved therapeutic purposeful interaction with them.

		MONITORING PATIENTS' SLEEP	ASSISTING WITH ACTIVITIES OF LIVING
Period 1	**Time Observed**	**% of time**	**% of time**
Grade G	3 h 30 m	0.0	9.6
Grade E	5 h 20 m	37.5	9.3
Grade D	26 h 50 m	6.8	18.7
Grade C	13 h 20 m	11.3	20.2
Grade A	1 h 40 m	0.0	0.0
Period 2			
Grade G	4 h 40 m	0.0	14.3
Grade E	10 h 10 m	32.8	11.4
Grade D	42 h 10 m	16.2	15.6
Grade A	1 h 50 m	0.0	9.1
Period 3			
Grade G	8 h 40 m	17.3	25.0
Grade D	26 h	15.4	23.7
Grade A	43 h 20 m	11.9	22.8

Table 7.4 Time spent by staff in observation of sleep and assisting with activities of living

Nurses spent between 9 and 25% of their time assisting patients' activities of living (Table 7.4). In the third period all three grades of nurse (G, D and A) spent between 23% and 25% of their time in this activity. More patients were attending CREST when Period 3 data were collected, which accounted for the additional nursing time spent on these activities (Chapter 8, Section 8.4). The information presented in Chapter 8, which examines patient dependency and activity while at CREST, suggests that nurses often had to help with activities of living because of patients' problems in maintaining self care. The selection of an activities of daily living assessment schedule based on Roper et al's (1980) model within the nursing framework was justified in the light of this finding.

7.4 Degree of adherence to nursing standards

Observation of nursing activity suggests that five of the nursing standards identified (detailed in Chapter 6, Figure 6.3) were adhered to reasonably well:

Assessment
Management of Incontinence
Prevention of Pressure Sores
Personal Hygiene
Freedom of Movement

The data collection method did not capture sufficient relevant information to identify the full extent to which 24-hour reality orientation was practised. Nurses' interactions with patients frequently embraced the concept of informal reality orientation; for example, in reply to a patient saying, "I want to go home", a nurse responded, "In the morning. It is 11.00 p.m. now and you are going to stay here tonight and we will take you home to your husband in the morning." All similar interactions were coded as "Purposeful therapeutic interaction" as they involved giving information in response to the patients' interaction. One formal reality orientation patient group was observed during Period 2 (Chapter 8, Section 8.4.3). This was conducted by a nurse who was not observed during that period. Therefore, this was not included within the nursing activity observation reported in this chapter. Consequently, although informal and formal reality orientation were practised by nursing staff, the data collected were not sufficient to assess adherence to this standard.

There were two additional nursing standards concerning patients' individual rights; that every effort should be made to maintain dignity and privacy of CREST patients, and that the cultural and religious needs of all patients should be met. The non-participant observation schedule did not contain sections referring specifically to either of these standards. However, in all three periods of observation patients appeared to be treated with dignity. They were never forced to look after themselves without help or left in states of visible distress. When patients were in a state of undress, using the bathroom or commodes by their beds, nurses used screens to protect privacy. In some instances, however, because of the open design of the accommodation, conversations between individual patients and nurses could be overheard by other patients. Individual care plans indicated that cultural and religious needs of patients were considered in line with the standard concerning these issues. For example, on a Friday, Mrs M.B., a Catholic, was never offered meat at breakfast.

7.4.1 Care planning standards

Data collected from the observation of nursing staff activity and the review of patient care plans are presented to determine whether the primary nursing and care planning standards were met. The care plans of the 34 patients who attended CREST in the 18 months during which the service was evaluated were reviewed. Four patients stopped attending CREST before a care plan was written. The remaining 30 were compared against the stated standard (Chapter 6, Figure 6.3), which stated that:

- each patient should have an individualised care plan by the fourth night of attendance at CREST;
- individual assessments should be completed using the framework for practice in co-operation with the patient's carer;
- each care plan should contain the patient's specific goals of care;
- care plans should be evaluated at least once every four weeks.

The results of comparing the 30 care plans against these standards are presented in Table 7.5. These indicate that most of the patients had individualised care plans written within two weeks of attendance at CREST. Twenty eight of the 30 care plans demonstrated that patients had been assessed by nurses using the nursing framework for practice and that patients' carers had been involved in this process. In order to establish the extent to which the framework for practice had influenced the care planning, the review of nursing notes involved identifying whether specific reference was made to the following items:

promoting patient independence in at least one activity of living,
promoting continence;
reducing nocturnal restlessness;
promoting sleep;
facilitating independence through social activities;
planning care specifically in response to carers' requests;

INDICATOR	TOTAL NO. OF CARE PLANS CONTAINING EVIDENCE
Complete assessment using the A/L framework present after the first four nights of a patient's attendance at CREST	28
Carer involved in assessment	28
Individualised care plan constructed within patient's first two weeks of attendance at CREST	20
Patient-orientated goals in care plan referring to:	
a) Promoting independence in at least one activity	23
b) Promoting continence	9
c) Reducing nocturnal restlessness and promoting sleep	14
d) Facilitating independence through social activity	2
e) Planning care specifically in response to carers' requests	19
Evaluation of programmes, frequency of review:	
a) Fortnightly	2
b) Monthly	14
c) Less frequently	14
Care plan was reviewed in conjunction with carers	19
Primary nurse took responsibility for assessing, planning and evaluating individual patients' care plans	27

Table 7.5 Number of care plans which demonstrated that care planning standards had been operationalised (maximum = 30)

Most care plans contained at least one patient-orientated goal relating to promoting independence. Goals concerning the other indicators were less frequently identified (Table 7.5). This was to be expected, in that initial assessments indicated that some patients were independent in toileting and did not have problems with nocturnal restlessness. Fourteen patients were assessed as having urinary incontinence but only nine of those patients' care plans contained appropriate individualised goals and prescriptions to alleviate their problems. No problems were identified for 16 patients concerning difficulties with sleeping on initial assessment, explaining why no reference was made to this factor in their care plans. However, many patients woke in the night and were settled by reassurance from nurses (Chapter 8, Section 8.4.1). Only two patients' care plans referred to facilitating independence through social activity, indicating that this was not a prime consideration when nurses were planning care. Details of carers' specific requests concerning care were explicit in 19 care plans. These ranged from requests from carers to wash patients' hair or shave male patients when they were at CREST to information concerning individual patients' specific likes and dislikes with regard to diet. In addition one care plan indicated that a catheter would be used rather than Paul's tubing for an elderly incontinent man because his wife could not cope with the Paul's tubing.

When care plans were reviewed carers were usually involved. Frequency of review depended on the length of time patients attended CREST. The two patients whose care plans were reviewed every two weeks only attended for two months. The 14 patients whose care plans were reviewed monthly had all attended for less than six months but more than two. The reasons why the other 14 care plans were not reviewed regularly were difficult to establish. There was evidence that the care plans of the 14 patients concerned had been reviewed shortly after the patients had first attended CREST. Eight of the 14 patients whose care plans were not reviewed regularly had used in-patient and respite care while still registered at CREST. The sporadic attendance of these eight patients may have been one of the reasons why primary nurses did not review the care plans. However, there was no evidence that the care plans were re-reviewed when these patients recommenced at CREST.

All but one primary nurse appeared to consider themselves responsible for assessing and planning the care for the patients who were allocated to them which was evident in the composition of 27 care plans. Three care plans were of a poor quality and did not demonstrate regular evaluation; these were all the responsibility of one primary nurse. There was no evidence that other primary nurses or the charge nurse brought this shortcoming to the responsible nurse's attention.

Review of the care plans demonstrated that the framework for practice influenced the assessment of individual patients. In the majority of instances, nurses and carers worked together to plan and evaluate care. The care plans illustrated that an activities of living framework was appropriate, in that it encouraged the identification of the types of problems that most patients experienced. The frequency with which care plans were reviewed failed to meet the standard agreed.

7.4.2 Primary nursing

The operational policy and nursing standards stated that each patient would have a primary nurse who would be responsible for planning and delivering the care. Initially only grade C nurses acted as associate nurses but later on grades D and above (primary nurses) also acted as associate nurses in the absence of the patient's primary nurse. At the end of the first year staffing consisted of the charge nurse, grade D and E nurses and nursing assistants (grade A). The grade D and E nurses were expected to function as primary nurses. Primary nurses were responsible for their own caseload and each was paired with another primary nurse so that they could act as associate nurse for each other.

Nursing assistants were allocated to work predominantly with two primary nurses and therefore came to know some patients better than others. The night co-ordinator's role was altered to ensure that nursing work was appropriately allocated in the absence of any patient's primary nurse, or if a primary nurse had too many patients to care for on any one night. This sometimes occurred when a primary nurse had also to act as associate nurse in the absence of the primary nurse with whom he/she was paired. When a primary nurse's workload was too heavy a nursing assistant was usually allocated to work with that qualified nurse.

Nursing assistants were not normally asked to care for an individual patient for a whole shift although occasionally the co-ordinator had to allocate work in this way because of staff sickness or absence. In these circumstances nursing assistants were asked to care for the patients of primary nurses with whom they normally worked. Nursing assistants (grade A) delivered nursing care to patients without necessarily working under the close supervision of primary nurses. For example, nursing assistants took patients to the bathroom and assisted them with toileting and hygiene without necessarily being overseen by a qualified nurse. These responsibilities fall outside the care assistant role described by Pearson (1988) but correspond to some extent with the duties taken on by nursing assistants in the ward described by Fall and Bond (1991). Thomas (1992) found that nursing assistants who worked closely with primary nurses in elderly care areas felt able to take initiatives in delivering care without close supervision. This occurred, she felt, because the nursing assistants came to know how the primary nurses with whom they worked expected care to be delivered. The permanent nursing assistant in CREST was aware of the primary nurses' expectations and appeared to respond in the way Thomas (1992) described, by taking on additional clinical responsibilities.

Although the term "primary nurse" was used in CREST its use was not necessarily synonymous with accepted definitions of primary nursing (Ersser and Tutton, 1991; Marram, 1976; Thomas and Bond, 1990). Thomas and Bond (1990) identified six criteria for categorising the organisational method used to deliver nursing care in wards for elderly people (Chapter 5, Section 5.3). The way in which nursing was organised at CREST is compared against these critera (Figure 7.1).

Figure 7.1 illustrates that the methods of organising care at CREST contained some features of primary nursing. The duty rota was organised to fit with the primary nursing system whenever possible with part time primary nurses being rostered to work on nights when the patients allocated to them were attending CREST. The primary nurses took responsibility for writing patients' care plans (Chapter 7, Section 7.4.1). Nurses were grouped into primary nurse/nursing assistant pairs, who worked together. The liaison between nursing staff and carers was conducted mainly by primary nurses, another feature of this method of organising care. It seems reasonable to conclude that the primary nursing approach was normally used for the assessment of patients' nursing needs, the planning of care and evaluation of that care.

The way in which care was actually delivered to patients did not reflect primary nursing as defined by Marram (1976) and Thomas and Bond (1990). Their descriptions state that primary nurses are responsible, even when away from the clinical area, for allocating the nursing work for their patients. However, in the absence of a patient's primary nurse the night co-ordinator was responsible for allocating the work at CREST. Sometimes work was allocated in such a way that a patient's personal care became fragmented. For example, a patient's medication would be given by the night co-ordinator but personal care tasks for the same patient were undertaken by a nursing assistant. The way in which care was

CRITERIA FOR IDENTIFYING ORGANISATIONAL METHODS OF NURSING (AFTER THOMAS AND BOND, 1990)	METHODS OF ORGANISATION USED TO DELIVER NURSING IN CREST
1. Grouping of nurses and time allocation to specific patients	1. Nurses grouped into teams headed by primary nurse groups. Initially nurses grouped into teams headed by a primary nurse. After one year groups contained only primary nurses and nursing assistants. Primary nurses also conducted associate nurse role for other patients (see exceptions in No. 2)
2. Allocation of nursing work	2. Separation of certain tasks according to Grade. For example, in the absence of a patient's primary nurse another qualified nurse would give that patient medication
3. Organisation of duty rota	3. The duty rota was organised to maximise primary nurse's duties in matching the attendance of patients for whom they were responsible
4. Nurses accountability for patient care	4. Primary nurses were held accountable for individual patient care by the CREST charge nurse. In the absence of the primary nurse another qualified nurse who was acting in an associate role accepted accountability
5. Responsibility for writing patients' notes	5. Primary nurses assessed, planned and reviewed patients notes in most cases (see Section 7.4.1)
6. Liaison with medical / paramedical staff including carers	6. Liaison between nursing staff and carers was primarily conducted by primary nurses. However, additional liaison between carers and nurses occurred when CREST staff were collecting and returning patients home. In these instances the nurses were not necessarily the patient's primary nurse. The charge nurse was mainly responsible for liaising with staff who worked during the day

Figure 7.1 A comparison between Thomas and Bond's (1990) features which distinguish methods of organising nursing and the approaches conducted at CREST

allocated in the absence of the patient's primary nurse appeared to relate to the workload of the staff on duty. It is difficult to decide whether this pragmatic approach to organising care should be categorised as falling within team nursing or task allocation. The problem of distinguishing between team nursing and task allocation is well documented and discussed in Chapter 5 (Durbin, 1981; Kron, 1981; Waters, 1985). Certainly, the data indicate that care delivery was practised using the primary nursing approach to some degree, but that alternative approaches were also employed.

Individual qualified nurses took responsibility for assessing patients' nursing needs, planning individual care programmes and evaluating care in line with the Patient's Charter which refers to the "named nurse" (Department of Health, 1991c). The delivery of nursing care became the responsibility of many team members, including the nursing assistants.

7.5 Summary

The operational policy, nursing framework and nursing standards changed to meet the requirements of patients and their carers. It was necessary to change the hours of CREST's operation so that patients were collected before 10.00 p.m. each evening. The morning traffic problem meant that nurses sometimes had to work until 9.30 a.m., which demanded an increase in nursing hours. The charge nurse and other team members decided to alter the grade mix of staff while remaining within the nursing budget to meet the changing requirements of the CREST service. The change in grade mix had implications for the method of nursing organisation.

Although primary nurses took the lead in assessing, planning and evaluating care, nursing assistants became increasingly involved in delivering care with minimum supervision. The defined nursing standards were adhered to with the exception of those relating to the method of nursing organisation and the frequency with which care plans were reviewed.

Nurse activity was observed to be predominantly patient-orientated with more than 70% of most nurses' time being spent in clinical activity rather than non-clinical work. Most clinical activity was spent in assisting patients with activities of daily living when they were awake and monitoring patients when they were asleep. Nurses were frequently involved in purposeful therapeutic interaction with patients. This finding was considered to be an indicator of individualised patient care, as was the amount of time spent by nurses communicating with patients' carers. The nursing framework for practice was used when assessing, planning and evaluating care for the majority of CREST patients (Figure 7.5). The activities of living framework for patient assessment was found to be appropriate, as most patients required some assistance with fulfilling at least one activity of living. Patients' carers were involved with nurses in planning patients' care. Patients' personal care tasks specifically requested by carers for nurses to undertake at CREST were included in the care plans.

In conclusion, the nursing staff's activity reflected CREST's operational policy and nursing standards. The philosophical approach to care was that the service should reflect the requirements of patients and their carers. Changes to operational policy were made to meet the needs of carers and patients, indicating that the philosophy of working in partnership with carers was, at least in part, achieved.

CHAPTER 8

CREST PATIENTS' ACTIVITY AND OUTCOMES

8.1 Referrals and admissions

Referrals to CREST were made by general practitioners, consultant psychiatrists, community psychiatric nurses, district nurses, staff at day centres, social workers, home help organisers and carers. More than 50% of the referrals were made by district nurses. During the first 17 months of CREST's operation 55 people, all but one of whom were over 60 years of age, were referred to CREST, 36 of whom were accepted. Of the remaining 19 who were assessed by either the charge nurse or senior staff nurse, CREST was not considered suitable for seven and 12 potential patients decided, together with their carers, that they did not wish to use the service. CREST was considered an unsuitable service for the following people by the nursing staff:

1. A man whose problems were predominantly behavioural and were not due to confusion or dementia.

2. A very confused woman who was awaiting Part III accommodation. She was unable to understand the concept of CREST and lived alone. The charge nurse believed that if she was accepted into CREST her admission to Part III would be delayed.

3. An elderly man who had severe dementia slept well throughout the night but his wife required additional help with getting him to bed. The charge nurse discussed the situation with the district nurse and social worker. As a result the patient's wife was assisted in applying for allowances and a referral to the Crossroads sitting service was made.

4. A woman in her eighties who was in long term hospital care was assessed for suitability to go home and live alone if she attended CREST. Following discussion between the CREST charge nurse and the patient's social worker it was decided that she was too confused to live alone and therefore the social worker arranged Part III accommodation for her.

5. A home help referred a woman who was wandering and described to be suffering from severe confusion. When the charge nurse conducted an assessment it became clear to her that the patient required a full psychogeriatric assessment. The psychogeriatrician visited following a request from both this person's GP and the CREST charge nurse. The patient was admitted to in-patient care under the Mental Health Act, 1983.

6. One elderly man was referred by the district nurse because his wife needed a rest. When the charge nurse visited to conduct an assessment it became clear that this wife needed more respite care than CREST would be able to offer. The patient was referred for short term in-patient respite care.

7. One patient who would have been suitable for CREST was too heavy to lift down the stairs; he lived in a maisonette and had no lift. It was therefore necessary to refer to Crossroads for a night sitting service to give his wife some relief.

Of the 12 people who were considered suitable by the nursing staff for attendance at CREST but who did not use places offered to them, the reasons given by them and their relatives were as follows:

1. Four carers decided that CREST would not be appropriate for their relatives.

2. One carer chose to continue to use the district nursing twilight service but said that his wife might come to CREST at a later date.

3. Four potential patients refused to consider attending CREST, two of whom were actively encouraged to attend by their carers.

4. One potential patient did not attend because his wife was admitted to hospital and he therefore had to be admitted to residential care.

5. Two potential patients were admitted to hospital before attending CREST, one for a cataract operation and another following a fall, neither of whom had previously attended CREST.

Of the 36 admissions to CREST in the period there is inadequate information on two patients, who attended for only one night each, to classify details about their age, carers and attendance at CREST, leaving 34 patients on whom to report.

8.2 Patient profiles

Individual patients' biographical details collected on admission, including age, sex, diagnosis and relationship with their carers, were analysed to develop a profile of CREST patients (Appendix 8.1).

The median age for male patients was 79.5 years (range 62-87 years). The median age for female patients was 80 years (range 57-95 years), four of whom were 90 years or over. Nineteen patients were suffering from Alzheimer's disease, 10 from multi-infarct dementia, four from non-specific dementia and one from Parkinson's disease.

The sample contained 17 men and 17 women, only three of whom lived alone (Appendices 8.1 and 9.1). One man lived in warden assisted accommodation and one woman lived alone, with her daughter, (her predominant carer) residing in the next street. The third patient, a woman, had no relatives or friends providing care. Fourteen of the 17 male patients were cared for by their wives, one was being cared for by a daughter, one by a sister. Of the 16 female patients who had carers, eight were cared for by their husbands, six by daughters, one was looked after by a male friend and another by her son.

Thirty one patients' dependency ratings were recorded on the Crichton Visual Analogue Scale within one week of their first attendance at CREST (Time A) by their primary nurses. A rating of under 30 on any sub-scale indicated that patients were generally able to fulfil that activity of daily living with minimal assistance, and a rating over 70 indicated that patients frequently required assistance. To identify the degree of behavioural dependence displayed each patient's total visual analogue score was calculated and placed within a ten point band, as described in Chapter 6, Section 6.3. The results in Figure 8.1 show that 19 patients were rated between 300 and 599 out of a possible 1,000, eight were rated between 0 and 299 and four between 600 and 800. These results indicate that eight patients were independent in their activities of living but most (those rated between 300 and 599) required some assistance with personal care and occasionally displayed behavioural problems associated with dementia. Four patients (those rated above 600) required much more assistance in order to meet their activities of living and a proportion of these patients also regularly displayed behavioural problems.

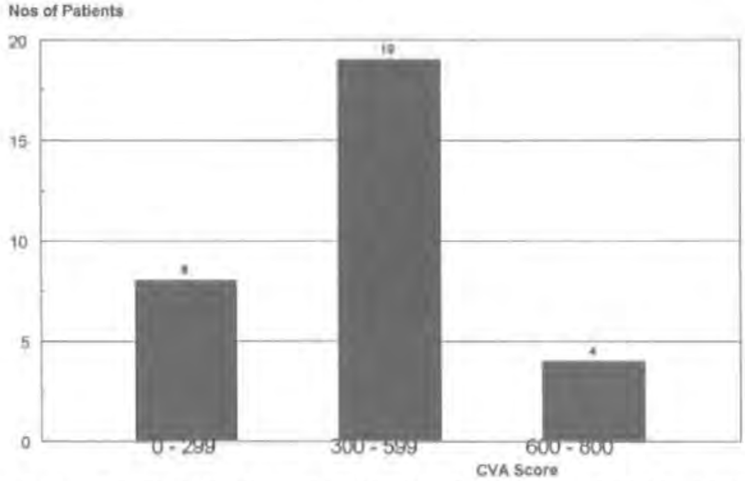


Figure 8.1 Total Crichton Visual Analogue scale scores for patients made by nursing staff: Time A

The six ratings of activities of daily living (mobility, conversation, feeding, dressing, sleeping and incontinence) revealed that the patient group as a whole was more independent in holding conversations and feeding themselves than in dressing or moving about unaided (Table 8.1). Most of the ratings for sleeping were less than 70. The largest number (n=12) of patients' ratings to fall between 31 and 69 were recorded on the sleep scale. The patients' sleeping patterns were an important issue for the CREST team because the service was designed for patients with dementia who experienced difficulty with sleep. The initial recordings conducted by primary nurses illustrated that a disturbed sleep pattern was a major problem for seven patients and 12 had mixed patterns. The remaining 12 patients were recorded as sleeping well at Time A by nurses.

n = 31	LESS THAN 30	31 - 69	MORE THAN 70
MOBILITY	11	6	14
CONVERSATION	20	5	6
FEEDING	25	3	3
DRESSING	7	7	17
SLEEPING	12	12	7
INCONTINENCE	14	8	9

Table 8.1 Patients' activities of living scores on the Crichton Visual Analogue Scale rated by nurses at Time A

The patient ratings recorded at Time A on four scales which related to behaviour commonly associated with people who have dementia, confusion, restlessness, moodiness and being difficult, are presented in Table 8.2. Eighteen patients were rated less than 30 on the restlessness scale, 15 were considered not to be confused and 14 to have little problem with mood. Less than a quarter of the patients were rated (over 70 on the scale) as consistently restless (6), confused (6), very moody (6) or difficult (3).

n=31	LESS THAN 30	31 - 69	MORE THAN 70
CONFUSION	15	10	6
RESTLESSNESS	18	7	6
MOODINESS	14	11	6
DIFFICULT	12	16	3

Table 8.2 Patients' activities of living scores on the Crichton Visual Analogue Scale rated by nurses Time A

The initial ratings recorded by primary nurses indicate that patients accepted into CREST displayed the behavioural problems associated with dementia of the Alzheimer's and multi-infarct types (Jacques, 1992; Lishman, 1987; Royal College of Psychiatrists, 1981). One measure of quality refers to a service's fitness for purpose (Healy, 1988), and can be measured by assessing whether a nursing service is being administered to an appropriate population (Healy, 1988; Manley, 1992). One aim of the service was to provide nursing care for patients at night who displayed behavioural problems and experienced difficulty in fulfilling their activities of living associated with dementia. The ratings of patients conducted by primary nurses at Time A using the Crichton Visual Analogue Scale indicated that the patient population accepted into CREST was appropriate.

8.3 Patterns of attendance

Of the 34 patients who attended CREST three attended for less than four nights before deciding not to return. The reasons for not continuing to attend were:

a) one patient who lived alone (Number 8) refused to attend;

b) one patient's wife (Number 22) did not like her husband going out at night;

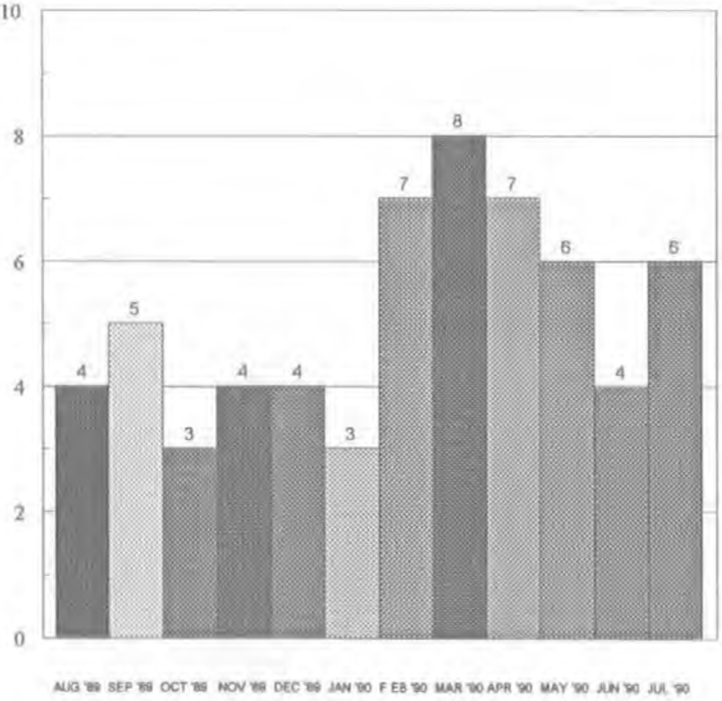
c) one patient (Number 32) found the ambulance journey too long and did not like CREST.

A retrospective review of records of patients' attendance revealed the length of time the remaining 31 patients were registered at CREST. Three patients attended for less than six weeks and three for more than one year; most came for between 12 and 36 weeks (Table 8.3).

REGISTRATION PERIODS AT CREST	NUMBERS OF PATIENTS
LESS THAN ONE WEEK	3
BETWEEN ONE AND SIX WEEKS	3
BETWEEN SIX AND 11 WEEKS	4
BETWEEN 12 AND 24 WEEKS	8
BETWEEN 25 AND 36 WEEKS	9
BETWEEN 37 AND 48 WEEKS	3
MORE THAN 49 WEEKS	4

Table 8.3 Registration periods of CREST patients

Most of the patients attended CREST for three or four nights a week with three patients using the service only once a week (Appendix 8.2). Fourteen CREST patients also regularly attended day hospital care. This did not affect their CREST attendance. The number of patients attending CREST per night between January 1989 and July 1990 varied between one and six. By August 1989 four patients were attending regularly. Figure 8.2 illustrates the average number of attendances for the year commencing August 1989, showing a peak of eight patients per night in March 1990. The fact that CREST was rarely full enabled patients to be admitted soon after referral. This meant that patients and their carers were able to choose when patients first attended rather than having to wait for access. It has been argued that the public will only really have choice about services when they are able to access them when required rather, than having to wait for the service of their choice because it is full, or select a less appropriate available service (Twigg, 1993).



<u>Figure 8.2 Average number of patients attending CREST per night, August 1989 - July 1990 inclusive</u>

8.3.1 Irregular attendance patterns

Seventeen patients used respite facilities while registered at CREST resulting in breaks in their attendance at CREST. All the respite care took place in hospital. No patient used social services' residential respite provision. To illustrate patient attendance at CREST, patients' attendance records over their period of registration at CREST were examined (Appendix 8.2). Seven patients' experiences are described to demonstrate their use of the services according to their specific needs and those of their carers. The reasons for their eventual discharge from CREST are also presented.

Mr B.H. - cared for by his sister (No.2)

Mr B.H., aged 85 years, with Alzheimer's disease, was registered for 22 weeks at CREST and received six weeks' respite care during this period (weeks 6 - 11) because his sister was admitted to hospital for a pre-booked operation. When she recovered he resumed attendance at CREST for three nights a week. In week 22 he became ill and was taken into hospital, where he died.

Mr B.G. - cared for by his wife (No.4)

Mr B.G., aged 79 years, with Alzheimer's disease who was heavily physically dependent attended CREST for four nights a week for 44 weeks before to being discharged to a private nursing home. He had respite care for a two week period five times during the 44 weeks that he stayed on CREST's register. The first period was a month after he had first attended CREST, the second was seven weeks later (weeks 14-15). He then attended CREST for nine weeks followed by two weeks' in-patient respite care. His respite care then increased to two weeks every six weeks at the request of his carer, district nurse and CREST primary nurse, because of his rapid physical deterioration and his wife's willingness to accept increased help.

Mrs M.B. - cared for by her daughter (No.9)

Mrs M.B., aged 95 years, who suffered from Alzheimer's disease and rheumatoid arthritis, was registered at CREST for 51 weeks. During this period she received respite care in weeks 16 and 17, 25 and 26 and 44 and 45. Her condition gradually deteriorated and for the last two weeks of her life CREST staff assisted her daughter in making her comfortable and putting her to bed in the evenings. She died peacefully at home.

Mrs N.S. - cared for by her husband (No.10)

Mrs N.S. aged 76 years, who suffered from multi-infarct dementia, attended CREST for nearly three years. During her first year's attendance she was admitted to respite care for three weeks (weeks 35-37) to give her husband a holiday. There is no information about her use of respite care after her first year's attendance at CREST, other than, when not receiving respite care, she attended CREST for three nights a week. She also used day care twice a week. She eventually died at home while still registered at CREST.

Mrs V.H. - cared for by her daughter (No.18)

Mrs V.H., aged 81 years, diagnosed as suffering from Alzheimer's disease, was registered at CREST for 28 weeks. During this time she had two periods of respite care in weeks 5 and 6 and 10 to 12. She also attended day care for four days a week, giving her daughter regular breaks from caring of approximately 20 hours four times a week. Following consultation between Mrs V.H.'s daughter, her GP and her CREST primary nurse, her admission to a private nursing home was arranged.

Mrs S.S. - cared for by her daughter (No.23)

Mrs S.S., aged 84 years, who suffered from Alzheimer's disease and had had a cerebral vascular accident, was registered at CREST for 32 weeks. She was admitted to hospital for treatment in weeks three and four and 12 and to respite care for a month in weeks 23 to 27. She then resumed attendance at CREST for four nights a week and attended day care twice a week. She was taken into hospital in week 32 and died that day.

Mr K.B. - cared for by his wife (No.34)

Mr K.B., aged 81 years, who suffered from Alzheimer's disease, was registered at CREST for four weeks. He received respite care during weeks three and four. His carer decided that she would rather use regular respite care; he did not return to CREST and was, therefore, discharged.

Fourteen patients became ill while attending CREST and required hospital admission. In addition one patient attended hospital for intensive rehabilitation (Appendix 8.2). Four patient vignettes illustrate how individuals used in-patient facilities.

Mrs M.L. - cared for by her daughter (No.6)

Mrs M.L., aged 91 years, with multi-infarct dementia, was registered at CREST for 15 weeks but was admitted to hospital in week 13 having suffered an extensive cerebro-vascular accident. She was discharged to long term hospital care at week 15 without returning to CREST.

Mr F.F. - cared for by his wife (No.7)

Mr F.F., aged 62 years, with multi-infarct dementia, was registered at CREST for 36 weeks and attended for four nights a week until week 20 when he was admitted to hospital following a severe cerebro-vascular accident. He stayed in hospital for 16 weeks and died without returning to CREST.

Mr S.B. - cared for by his wife (No.12)

Mr S.B., aged 84 years, with Alzheimer's disease, was registered at CREST for 66 weeks and was admitted to in-patient care in weeks 7 and 8 when he was successfully treated for a chest infection. He then attended CREST regularly for two nights a week until week 20. He was then unwell for a period at home and attended CREST for only one night over a two month period. He received respite care in weeks 32 and 34. In his 34th week of registration he recommenced regular attendance at CREST for four nights a week until week 41. He had another period of physical illness at home followed by three weeks' respite care. He then refused to attend CREST in week 51 and 52 but remained on the register because his wife was keen for him to return. He attended regularly until week 66, when he was discharged home when he became too frail to travel. A night sitter service was arranged on his discharge.

Mrs L.M. - cared for by her daughter who lived in the next street (No.24)

Mrs L.M., aged 86 years, with Alzheimer's disease, regularly attended CREST for 26 weeks but was an in-patient during weeks 12 to 14 following a transient ischaemic attack. In week 19 she had a severe cerebro-vascular accident and following seven weeks in hospital was discharged to a private nursing home. She remained registered at CREST until week 26, when it was decided she would remain in long term residential care.

Irregular attendance at CREST also resulted from patients refusing to attend. Three patients refused following brief attendances which resulted in their discharge by mutual agreement between their carers and primary nurses. Two other patients who also refused to attend are described.

Mrs G.N. - cared for by a male lodger (No.5)

Mrs G.N., aged 73 years, who was reported to have Alzheimer's disease but had also previously been admitted to in-patient psychiatric care for treatment for a personality disorder, regularly refused to attend. Although registered at CREST for 78 weeks, her attendance was sporadic after the first 10 weeks. She came for two nights in weeks 13, 28, 29 and 30; and one night in weeks 15, 17, 22 and 41. She was admitted to respite care in weeks 31 and 32 and subsequently refused to get into the CREST ambulance up to week 52. Her carer still wished her to attend CREST and her primary nurse agreed to try to encourage her to attend once a week for the following three months. The retrospective review of her care plan indicates that she attended CREST five times between weeks 41 and 78, when she was finally discharged.

Mr J.V. - cared for by his daughter (No.15)

Mr J.V., aged 80 years, was registered at CREST for 26 weeks. During this period his sleeping pattern improved and his carer felt more able to cope. When he realised this he refused to come to CREST, having attended for four nights a week on a regular basis without apparent reluctance. By mutual agreement between the patient, carer and primary nurse he was discharged on the understanding that he would be re-admitted in the future if necessary.

Individual patients used respite care and spent periods in hospital for treatment during their periods of registration at CREST. The frequency and length of time spent in hospital for treatment and/or respite care varied for each patient (Appendix 8.2). The relationship between the use of respite care and hospital care resulting from deterioration are considered in relation to patient outcome in Chapter 8, Section 8.5.

8.4 Patient activity

Patient activity was observed for three periods, each of three nights' duration. One night's observation per month was conducted as indicated in Chapter 6. On each occasion except one, two patients were observed from the time they were collected at home until they returned home the next morning. During the first period of data collection, on one night when taxis were used to transport patients, one patient was not observed on his morning journey from CREST to his home. Eighteen patient activity data sets were collected, six in each period (Appendix 8.3). Twelve patients were observed for one night's duration and three for two nights. One of the patients was observed for two consecutive months' attendance in Period 1, one for one night in both Periods 1 and 2 and one for one night in both Periods 2 and 3. Data were collected on patient activity for 69 hours 20 minutes (416 observations) in Period 1, 71 hours 10 minutes (427 observations) in Period 2 and 82 hours 10 minutes (493 observations) in Period 3. Table 8.4 indicates patient activity while travelling to, from, and when at CREST in all three periods.

CLIENT ACTIVITY CODE	PERIOD 1	PERIOD 2	PERIOD 3
	%	%	%
AD Assistance with dressing/undressing	1.20	1.64	1.01
AE Assistance with eating	0.72	1.17	0.20
AH Assistance with hygiene	2.88	0.47	1.22
AM Assistance with mobility	2.64	4.00	2.83
AT Assistance with toileting	3.61	2.10	1.22
AS Assistance with preparation for sleeping	1.92	1.87	1.42
BP Behavioural problem i.e. shouting	0.0	7.49	2.43
SC Self contained behaviour	14.18	13.81	17.04
I Independent behaviours e.g. dressing/eating/drinking	5.29	3.51	11.36
IB Individual behavioural programme being conducted	0.96	0.0	0.0
IN Interacting with nurse	7.21	7.49	6.90
IP Interacting with other patients	1.44	0.0	3.04
NESC Nurse encouraging self care	1.20	0.94	0.0
NR Recreation with nurse	0.72	0.47	1.01
PR Recreation/interaction with other patients	0.0	0.0	0.0
ROG Reality orientation group	0.96	0.0	0.0
RPC Receives physical care/check i.e. wound/pressure area/medication	1.20	0.47	0.20
S Sleeping	53.85	54.10	50.10

Table 8.4 Patient activity: time observed in each category

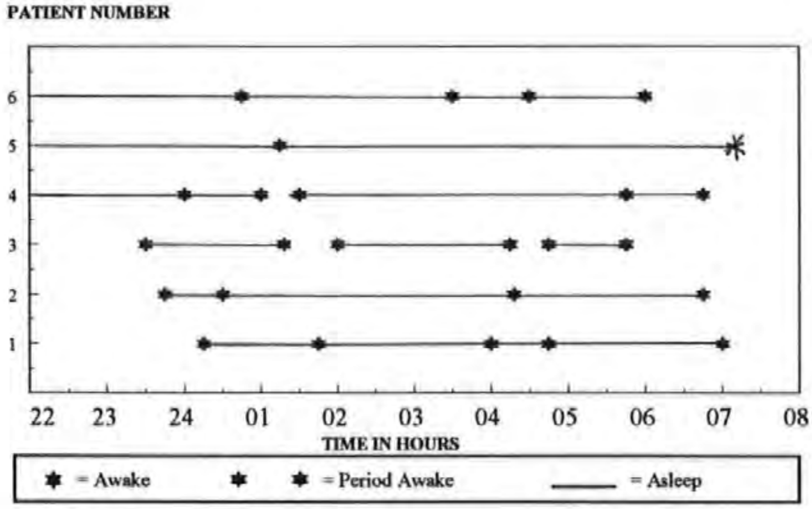
Sleeping

The majority of patients' time was spent sleeping in all three time periods, ranging from 50-54% (Table 8.4). Taken as a percentage, it seems that patients slept for long periods undisturbed. In fact, most of the patients woke several times during the night, requiring attention. Figure 8.3 shows the times that they woke. Although few were awake for long periods they usually needed assistance with toileting, or reassurance before returning to sleep. Two of the patients observed called out frequently during the night and could only be settled by verbal reassurance or a hot drink.

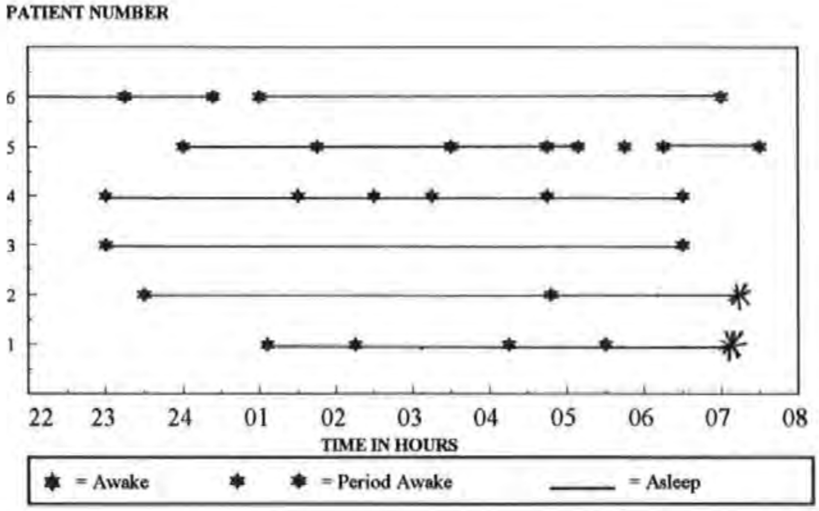
Activities of daily living, encouragement of self care independent behaviour

Patients received assistance with activities of living on a one to one basis for 13% (54 observations) of the time in the first period, 11% (48 observations) in the second and 8% (39 observations) in the third. This gradual reduction in assistance can be interpreted in two ways; either that patients were gaining more independence in self-care, or that they received less assistance from nurses than they actually required in the later periods. The amount of nursing time spent in assisting patients with activities of living varied between the three periods (Chapter 7 Section 7.3.2 Table 7.4) with the highest proportion of nursing time spent on this activity being observed in Period 3 (between 23% and 25%). The proportion of time that patients received encouragement for self care from nurses was 1% in the first two periods of observation an activity which was not observed in Period 3. They displayed independent behaviour for 5% of their time at CREST in Period 1, 4% in Period 2 and 11% in Period 3. Taken together these observations suggest that nursing staff were encouraging patients to undertake their own activities of living and maintain independence in self care in the third

PERIOD 1



PERIOD 2



PERIOD 3

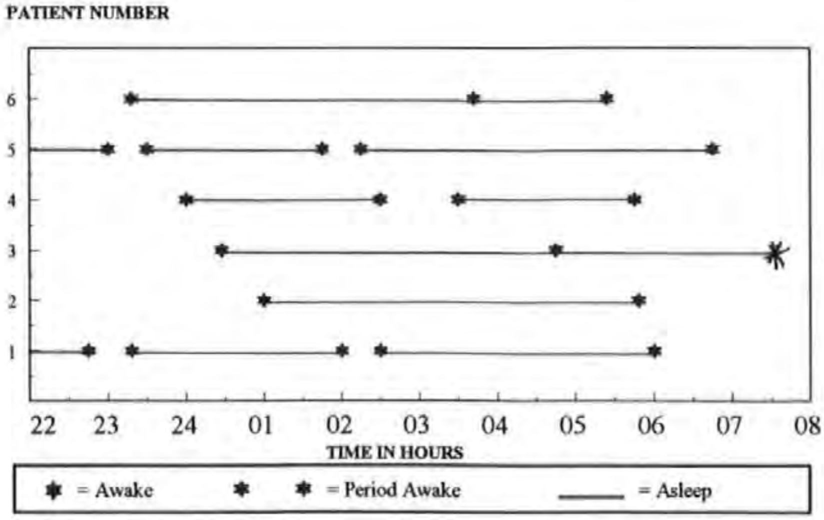


Figure 8.3 Patients' sleeping patterns while at CREST

period and assisting only those patients who were unable to undertake these activities unaided.

Self contained behaviour

Patients spent increasing amounts of time in self contained behaviour between Periods 1 and 2 (14%) and period 3 (17%). This included some patients who spent time in front of the television without appearing to really watch it; other patients had books or newspapers on their knees but their concentration spans for reading appeared to be very short. When travelling in the ambulance, if patients sat quietly self contained behaviour was recorded. Although it was to be expected that the group of patients attending CREST would spend some time in self contained behaviour, 17% is high given that, in Period 3, they also spent 50% of their time sleeping. Patients, therefore, spent approximately a third of their time awake in self contained behaviour while attending CREST in the third period. Patients who suffer from dementing illnesses are frequently restless, noisy and distressed (Lishman, 1987). Therefore, the finding that patients spent considerable periods without displaying overt distress or disruptive behaviour could be perceived as a positive outcome of nursing.

Reality orientation groups

Patients were not observed taking part in reality orientation groups in Periods 2 or 3 and spent less than 1% of their time in this way in Period 1. The group observed in Period 1 was led by a nurse who was not being observed that night, explaining the absence of any recorded nursing time in this activity. It appears that because patients often arrived at CREST after 8.30 p.m., formal reality orientation groups were not organised on a regular basis. However, reality orientation on a one to one basis did occur; for example, when travelling to and from CREST, patients often recognised particular landmarks or asked questions about their location. At this time nurses answered questions using the principles of reality orientation. For example, one patient remarked, as a Sainsbury's supermarket was passed, that there used to be a Sainsbury's store at that point. The nurse explained how Sainsbury's now had orange and brown lettering and was a supermarket but that the patient's memory of marble counters and gold and brown lettering was, in fact, accurate.

Recreation and interaction between patients and nursing staff

At no time were patients observed in formal recreation activities with each other, such as playing cards. They were observed talking to one another in Periods 1 and 3, although this was infrequent (Table 8.4). Recreation and interaction with nursing staff were observed to be consistent over time:

Recreation %		**Interaction %**
0.7	**Period 1**	7.2
0.5	**Period 2**	7.5
1.0	**Period 3**	6.9

Behavioural problems

Although patients were observed to shout and, in two instances, to be physically aggressive, this behaviour was not common in the total patient group. The activity was observed as follows:

Period 1 - 0

Period 2 - 7.5%

Period 3 - 2.4%

Travelling

The times spent travelling to and from home to CREST were recorded and noted for each patient. The longest journey time observed for any patient was two hours 30 minutes on a return morning trip; the shortest was five minutes. Most patients spent between 30 minutes and an hour in the ambulance in the mornings and again in the evenings. Travel times were reduced when taxis were used, in that one covered a specific part of the catchment area. It was not possible to carry heavy, physically dependent patients in taxis.

The results collected from observing patient activity are consistent with those from nursing staff activity observations. When patients were at CREST they received encouragement for self care and, when necessary, assistance from nursing staff to fulfil activities of living. These findings suggest that the nursing model for care was used in practice (Chapter 6, Figure 6.2). Recreation and interaction between patients and nursing staff was observed in all three periods. In addition, patients spent time in self contained behaviour indicating that they were allowed some freedom and choice in whether they mixed with other patients and staff.

8.5 Patient outcomes

8.5.1 Patient outcomes: Crichton Visual Analogue Ratings

Dependency ratings were recorded using the Crichton Visual Analogue Scale as follows:

Within one week of attendance	(Time A)
Six weeks following initial attendance	(Time B)
12 weeks following initial attendance	(Time C)
Six months following initial attendance	(Time D)

Ratings were conducted independently by patients' carers and their primary nurses (Appendices 8.4 and 8.5). When sample size was sufficient Wilcoxon Matched Pairs Signed Ranks Tests were used to test the null hypotheses that:-

> "There is no change in patients' dependency scores as rated using the Crichton Visual Analogue scale between Times A and B, A and C, A and D,B and C, B and D and C and D."

Patients' total dependency ratings as recorded by nurses were not significantly different between any of the time periods (Table 8.5). There was no significant difference in dependency as recorded by carers between the time periods.

There was no significant difference in dependency as recorded by carers between time periods except in one instance when patients ratings decreased, Time B with Time D (n=8, Wilcoxon T - 4, $p<0.05$) (Table 8.6). Using a probability level of <0.05, 5% of comparisons can be expected to be significant by chance (Campbell, 1967). It could be that the Time B with Time D result was due to chance given that the other comparisons with Time D were not significant. The small sample size (n=8) included two patients whose ratings increased by a small amount between Time B and Time D (No. 18 by 15 (864 to 906) and No. 9 by 43 (873 to 918) which may have inflated the significance level. The other six patients' ratings all decreased during this period with a range of 42 to 220. Given these reasons, it is concluded that the significant result from Time B with Time D may not be clinically valid and should, therefore, be regarded with suspicion.

NURSE RATINGS OF PATIENTS PERIOD OF COMPARISON	NUMBER OF PAIRED CASES	WILCOXON T STATISTIC	P
Time A with Time B	24	119	ns
Time A with Time C	18	81	ns
Time A with Time D	11	27	ns
Time B with Time C	18	79	ns
Time B with Time D	11	29	ns
Time C with Time D	9	13	ns

Table 8.5 Comparison of patients' dependency ratings on the Crichton Visual Analogue Scale as recorded by primary nurses

CARER RATINGS OF PATIENTS PERIODS OF COMPARISON	NUMBER OF PAIRED CASES	WILCOXON T STATISTIC	P
Time A with Time B	18	51	ns
Time A with Time C	16	58	ns
Time A with Time D	10	21	ns
Time B with Time C	14	50	ns
Time B with Time D	8	4	<0.05
Time C with Time D	9	12	ns

Table 8.6 Comparison of patients' dependency ratings on the Crichton Visual Analogue Scale as recorded by carers

Patients who attended CREST for six months (Time A with D) did not become significantly more dependent as rated by nurses or carers. This result can be interpreted in two ways; either that CREST had no detrimental effect on patients or that it had a positive effect. The literature reviewed in Chapter 2 illustrates that elderly patients who suffer from Alzheimer's disease will normally experience a steady decline in their ability to perform activities of living unaided and will experience changes in behaviour associated with cognitive decline, over a period of three to seven years. Patients with multi-infarct dementia also deteriorate, although this is more likely to occur in a step-like fashion associated with small cerebral infarcts. When the progressive nature of dementia is considered it is a positive outcome to find that a group of patients suffering from dementia did not become increasingly dependent over a six month period of attendance at CREST.

It had been anticipated that nursing intervention may have affected specific behaviours as recorded on each sub-scale of the Crichton Visual Analogue Scale. Therefore, analysis was conducted using the Wilcoxon Matched Pairs Signed Ranks Test to test the hypothesis:

> "That there is no change in patients' dependency scores as rated on each sub-scale of the Crichton Visual Analogue Scale between times A and B, A and C, A and D, B and C, B and D and C and D."

The hypothesis was tested using data rated by carers and data rated by nurses separately. Of 120 tests, only four significant differences emerged. Three of these showed a reduction in patients' dependency ratings over a period of attendance at CREST

(Table 8.7). The fourth significant difference concerned an increase in patients' dependency ratings by carers on Confusion between their first week of attendance at CREST (Time A) and six weeks after initial attendance at CREST (Time B) (n=18, T=23.5, p<0.001).

SUB/SCALE AND RATER	TIME COMPARISON	NO. OF PAIRED CASES	WILCOXON T VALUE	P
SLEEP rated by nurses	Times A and B	24	60	<0.001
SLEEP rated by nurses	Times A and C	18	35	<0.05
FEEDING rated by nurses	Times A and C	18	35	<0.05

Table 8.7 Reductions in patients' dependency ratings, over a period of CREST attendance, on sub-scales of the Crichton Visual Analogue Scale

Using a probability level of <0.05, 5% of the 120 comparisons can be expected to be significant by chance (Campbell, 1967). The four significant results that emerged are likely, therefore, to be chance findings suggesting that no true differences exist. Consequently, it was decided to investigate these results from a clinical perspective. The medians of patients' ratings as scored by primary nurses and carers were calculated to assist in interpreting potential clinical reasons for the results (Tables 8.8 and 8.9).

The changes in nurses' ratings of patients' levels of feeding between Time A (median 5.0) and C (median 0.5) were, in fact, minimal for individual patients (Table 8.8). When completing the scale, raters must mark the line at a point which reflects their perceptions of the patients' level of confusion. Marks across periods may differ by a few points even though the rater intended to indicate no change; the raters did not have earlier ratings as reference when making later ratings.

TIME RECORDED	**A**	**B**	**C**	**D**
PATIENT NUMBERS	**n = 31**	**n = 24**	**n = 18**	**n = 11**
CRICHTON VISUAL ANALOGUE SCALE ↓				
Mobility	68.0	50.0	68.5	57.0
Confusion	44.0	33.0	50.0	49.0
Helpful	48.0	32.0	53.5	52.0
Conversation	23.0	26.5	35.0	60.0
Feeding	5.0	2.5	0.5	6.0
Dressing	80.0	82.5	68.5	89.0
Sleep	49.0	34.0	26.0	21.0
Continence	34.0	27.5	39.5	46.0
Restless	18.0	24.0	29.5	37.0
Mood	39.0	39.0	47.0	31.0
Total Visual Analogue Scale	**415.0**	**395.0**	**417.5**	**411.0**

Table 8.8 Patient ratings (medians) by nurses on sub-scales of the Crichton Visual Analogue Scale

TIME RECORDED	**A**	**B**	**C**	**D**
PATIENT NUMBERS	**n = 27**	**n = 18**	**n = 16**	**n = 10**
CRICHTON VISUAL ANALOGUE SCALE ↓				
Mobility	51.0	65.0	83.0	86.5
Confusion	49.5	74.5	70.5	82.0
Helpful	68.0	73.5	72.5	48.0
Conversation	69.0	79.5	79.0	71.5
Feeding	16.5	34.5	21.0	35.5
Dressing	94.5	94.0	94.0	95.5
Sleep	71.5	76.0	71.0	60.5
Continence	50.0	88.5	67.0	80.5
Restless	50.0	63.5	51.5	49.0
Mood	32.0	51.5	51.0	38.0
Total Visual Analogue Scale	**511.0**	**598.5**	**533.5**	**574.5**

Table 8.9 Patient ratings (medians) by carers on sub-scales of the Crichton Visual Analogue Scale

The nurses' ratings of patients' sleeping patterns were of particular clinical interest; the reduction in median score across the periods from 49 to 21 (Table 8.8) indicated that patients were perceived to be sleeping better following admission to CREST. This perception was not supported by the carers' ratings, which were consistently higher than the nurses' and did not change much over time (Table 8.9). It might be because nurses who were on duty attended to patients promptly when they woke up thus ensuring patients' sleep loss was minimal. Carers are more likely to be disturbed by patients waking because they also want to sleep and so wakeful patients are more of a problem for carers than for nurses. The patterns of patients' sleep (Figure 8.3) suggest that many CREST patients woke frequently for short periods. This finding supports the interpretation that nurses were less disturbed than carers by patients' abnormal sleep patterns and thereby rated patients as less dependent than did carers on this sub-scale.

The changes in patients' ratings conducted by carers on the Confusion sub-scale are difficult to interpret. It is possible that the deterioration recorded between Times A and B (Table 8.9) occurred because patients became increasingly confused when first attending CREST, with the Time A ratings reflecting patients' level of confusion before arrival at CREST. Alternatively, it could be that once carers had agreed to their relative or friend attending, they felt that the level of confusion must be high because the patient warranted a CREST place. A proportion of patients who use respite facilities have been reported to suffer increased confusion attributed to attendance, a factor which may have contributed to some patients ceasing to attend CREST (Grant, 1991; Rai et al, 1986; Smith and Cantley, 1985).

8.5.2 Patient attendance and discharges

The retrospective review of patients' nursing notes provided data on reasons for discharge from CREST (Table 8.10). Thirty one patients attended for less than a year. Three patients were registered at CREST for more than a year; Mrs G.N. attended sporadically over an 18 month period, Mrs N.L. attended regularly for 136 weeks and eventually died at home and Mr S.B. who was discharged after 66 weeks when he became too frail to attend CREST. These patients' attendance histories are described in Chapter 8 Section 8.2.

REASONS FOR DISCHARGE FROM CREST	TOTAL NUMBER n=34
Died while registered at CREST	8
Admitted to long term care	13
Discharged home	10
Registered for more than one year	3

Table 8.10 Reasons for patient discharge from CREST

To identify whether patients' outcomes were affected by their dependence on admission, Kruskal-Wallis analysis of variance of ranks procedure was used to test the null hythosesis:

> "There is no difference between patients' dependency scores as rated with the Crichton Visual Analogue Scale at Time A (within one week of admission) and patient outcomes."

Thirty one patients were rated by nurses at Time A (Appendix 8.4); three attended for more than one year, nine were discharged home, seven died and 12 were admitted to long term care. Analysis of the patient ratings by nurses at Time A and patient outcomes demonstrated no significant differences between the four groups (H=5.72, df=3, ns).

Twenty seven patients were rated by carers at Time A (Appendix 8.5); three attended for more than one year, seven were discharged home, seven died and 10 were admitted to long term care. Analysis of the patient ratings by carers at Time A and patient outcomes demonstrated no significant differences between the four groups (H=6.8, df=3, ns).

Of the 34 patients on whom data were collected, 19 suffered from Alzheimer's disease, 10 from multi-infarct dementia and five from non-specific dementia. It was not possible to analyse the relationships between patient outcome and diagnosis statistically because of the small sample sizes (Table 8.11). However, a higher proportion of patients with multi-infarct dementia (40%) died while registered at CREST compared to those who suffered from Alzheimer's disease (16%). Similar percentages of patients were admitted to long term care with diagnosis of Alzheimer's disease (37%) and multi-infarct dementia (40%).

TOTAL PATIENT POPULATION n=34	**ALZHEIMER'S DISEASE n=19**	**MULTI-INFARCT DEMENTIA n=10**	**NON SPECIFIC DEMENTIA n=5**
Died n=8	3	4	1
Long Term Care n=13	7	4	2
Discharged n=10	7	1	2
Attended more than 1 year n=3	2	1	0

Table 8.11 Patient outcome and underlying diagnosis

In order to establish whether particular services enabled carers to keep patients at home, the reasons for patients' discharge from CREST were considered in relation to the use of respite care, in-patient treatment and day care (Table 8.12). Individual patients and their carers required different levels of support and intervention from health and social services while attending CREST. Although no clear trends were identified regarding use of particular services and patient outcome seven of the 13 patients who were discharged to long term care had used respite care during their registration at CREST (Table 8.12). One possible reason for this could be that once carers accepted residential respite care they gradually accepted that long term care would be appropriate for their relative or friend.

TOTAL PATIENT POPULATION n=34	RESP. CARE ONLY n=7	IN-PATNT ONLY n=5	DAY CARE ONLY n=1	RESP. CARE + IN-PATNT CARE n=3	RESP. CARE + IN-PTNT CARE + DAY CARE n=2	RESP. CARE + DAY CARE n=6	IN-PATNT + DAY CARE n=5	NONE n=5
Died n=8	1	1	0	1	2	0	3	0
Long Term Care n=13	4	3	0	0	0	3	1	2
Discharged n=10	2	1	1	1	0	1	1	3
Attended more than one year n=3	0	0	0	1	0	2	0	0

Table 8.12 Patient outcome and use of other types of respite, in-patient and day care

Of the 13 patients who went into long term care six were admitted to private nursing homes and six to in-patient mental health facilities. Only one patient was admitted to social service Part III accommodation. During the period that data were collected the health authority provided more than 100 in-patient beds for elderly mentally ill people but these were being reduced. Therefore, some patients were offered private nursing home facilities which were fully funded by the health authority with future funding assured.

Any relationship between admission to in-patient care and death was tested using Fishers exact test on the data in Table 8.13, and a significant difference emerged, $p<0.011$. This result could mean either that patients were admitted to in-patient hospital care because they were ill and subsequently died, or that in-patient care had a detrimental effect on patients. In fact, seven of the eight patients who died while registered at CREST were admitted to in-patient care because their health deteriorated. As could be expected, cerebro-vascular accidents and chest infections were the most frequent causes of death (Lishman, 1987).

TOTAL PATIENT POPULATION n=34 OUTCOME	IN-PATIENT CARE	NO IN-PATIENT CARE
Died n=8	7	1
Alternative outcomes n=26	8	18

Table 8.13 Two categories of patient outcome: death and alternatives and the use of in-patient care

Patient outcomes were considered in terms of patients' relationship with carers (Table 8.14). Half the patients cared for by husbands were admitted to long term care compared to a third of those cared for by wives, suggesting that husbands may have been offered long term care for CREST patients more frequently than wives. Alternatively, husbands might have been more assertive in requesting long term care compared to wives. It has been argued that women may perceive caring as an integral part of their role, thus reducing their ability to both request and accept help (Finch and Groves, 1983).

TOTAL PATIENT POPULATION n=34	HUSBAND n=8	WIFE n=14	DAUGHTER n=7	OTHER n=5
Died n=8	2	3	2	1
Long term care n=13	4	5	3	1
Discharged n=10	1	5	2	2
Attended more than 1 year n=3	1	1	0	1

Table 8.14 Patient outcome and carer relationship

Three of the seven patients cared for by their daughters were admitted to long term care, as was the female patient cared for by her son (Table 8.14). The reasons for these admissions varied: the son carer became ill and could no longer care for his mother, one patient was admitted to hospital following a cerebro-vascular accident and her daughter felt unable to continue.

Of the ten CREST patients who were discharged home, three (numbers 8,22 and 32) refused to return after less than four nights' attendance (Chapter 8, Section 8.3). Another patient did not like CREST and was discharged home, with his carer's agreement, after four weeks' attendance. One patient refused to attend after 26 weeks' registration at CREST having received respite care in weeks eight to 13. The patient's primary nurse and carer requested regular respite care for this patient, which was made available for two weeks in every six weeks. One patient stopped attending CREST after 21 weeks due to "family problems"; the patient's carer said she did not wish to explain the reasons more fully. Of the remaining four patients discharged home, one did so because her carer's health improved, and three because of improvements in their own health.

Of the three patients whose were discharged because their health improved, one was clearly related to attendance at CREST. This 81 year old man had presented with a very disturbed sleep pattern, which improved so much that his carer felt able to care for him at night (Chapter 8, Section 8.5). Another patient discharged home, and who had Parkinson's disease, became more independent because of a change in his drug regime which was altered following a brief in-patient admission. The third patient was discharged because a short term disability with his hand improved, so increasing his independence.

The case histories indicate that each patient had individual reasons which influenced their outcome. Further discussion concerning the eventual outcome of CREST patients is presented in Chapter 9, together with information from carers' interviews.

8.6 The effects of CREST: a summary

Fifty five people were referred to CREST during the first 17 months of operation. The effects of CREST on patients started at their time of referral. Although 19 patients who were assessed by the CREST charge nurse or senior staff nurse were not admitted to the service, the assessment process resulted in alternative care provision being arranged for two of them (Chapter 8, Section 8.1). Data were collected on 34 patients, 17 male and 17 female. The median age for patients on admission was 79.5 years for men and 80 years for women. Thirty one patients were rated on the Crichton Visual Analogue Scale by nurses within one week of admission (Time

A). Of these, 19 were rated in the middle range, indicating that they required some assistance to fulfil activities of living and occasionally displayed behavioural problems associated with dementia. Eight patients were more independent in self care while four required extensive assistance to meet daily living requirements. These initial assessments by nurses indicated that CREST patients displayed behavioural problems associated with dementia. This finding demonstrates that the service was being administered to the population that CREST was designed to serve (Chapter 6).

Patients' patterns of attendance at CREST were diverse, ranging from one night to 136 weeks, with some patients attending for one night a week and others for four nights a week. Half attended for periods of between 12 and 36 weeks' duration. Irregular patterns of attendance were associated with the use of residential respite care, admission to hospital for treatment and, in some instances, refusal to attend.

The results of observing patients when at CREST demonstrated that the majority of their time was spent sleeping, although several patients woke at intervals during the night and required nursing attention. The data collected from observing patients' activity were consistent with the observations of nursing staff activity at CREST. Patients were observed to receive encouragement to conduct self care and help to fulfil their own daily living needs from nurses when necessary. Formal recreational activities such as playing cards were rarely observed, although social interaction was identified (Chapter 8, Section 8.4.4). Patients spent periods of time in self contained behaviour, which can be perceived as a positive outcome of nursing for the population served. These findings suggest that the nursing model for care (Chapter 6, Figure 6.2) was used to structure the care, in that nurses assisted patients when necessary while encouraging independence.

No significant change in patients' dependence as rated by either nurses or carers using the Crichton Visual Analogue Scale was identified over a six month period of attendance. This finding was consistent when ratings taken at Time A (within one week of attendance) were compared with Time B (within six weeks of attendance), Time C (within 12 weeks of attendance) and with Time D (Chapter 8, Section 8.5.1) It is concluded that this result was a positive outcome of CREST, in that patients who suffer dementia could normally be expected to become increasingly dependent over a six month period (Jacques, 1992; Lishman, 1987).

Patient independence was promoted at CREST through the successful application of the stress reduction, activities of living model of nursing (Chapter 6, Section 6.3). Patients maintained their individual levels of functioning in activities of living, and disturbed behaviour associated with dementia did not increase. The consistency of patient dependency ratings and the results from observing nursing staff and patients' activity at CREST indicate that the model of care was applied in practice.

Comparison of patients' ratings on individual sub-scales of the Crichton Visual Analogue Scales (120 tests) identified four significant differences, which could have been due to chance;

therefore, it was decided to investigate these results from a clinical perspective. The nurses' ratings of patients' sleeping patterns indicated a reduction across the periods from 49.0 (Time A) to 21.0 (Time D). Carers' ratings were consistently higher than nurses' ratings on this scale and did not change over time (Time A = 71.5, Time D = 68.0). It is concluded that the difference in ratings by nurses and carers is associated with nurses being on duty when patients wake and responding to their needs quickly with minimal loss of sleep to patients. Carers, however, have their own sleep disturbed when patients wake at home and consequently both parties are more disturbed by patients waking.

Of the 34 patients who attended CREST, three did so for more than one year, eight died while registered at CREST, 10 were discharged home and 13 were admitted to long term care. No significant difference was found between patients' Crichton Visual Analogue Scale ratings by nurses and carers at Time A (within one week of admission) and patient outcome. No trends emerged concerning patients' diagnoses and outcome (Table 8.11).

A relationship between the use of in-patient care and patient death was identified. This was attributed to patients being admitted to hospital because they deteriorated and became ill, as opposed to in-patient care having a detrimental effect on CREST patients. CREST patients used individualised packages of care including respite services, day care and in-patient facilities (Table 8.11). Patients and their carers also used other community care services which are detailed in Chapter 9. The data presented in this chapter indicate that night care facilities were rarely sufficient for the patients who attended CREST without supplementary services. Despite the difficulties of attributing patient outcome to attendance at CREST because of the mixed provision of care most patients received, it is concluded that the care at CREST facilitated patient independence.

No trends between patients' levels of dependence at Time A (within one week of admission), the use of other services, relationship to carers and patient outcome were identified. A variety of factors contributed to individual CREST patient outcomes. The information from carers' interviews reported in Chapter 9 (Section 9.3) is considered in relation to patient outcomes in Chapter 10 (Section 10.4).

CHAPTER 9

CARER EXPERIENCES AND OUTCOMES

9.1 Carer profiles

Twenty seven of the thirty four patients' carers were interviewed within a week of the patient's first attendance at CREST. Three carers did not wish to be interviewed because their relatives stopped going to CREST after one night's attendance. The remaining four carers were not interviewed because the people for whom they provided care were admitted to CREST in the last two weeks of the data collection period. One data collector was ill at that time and the second was attempting to conduct follow-up interviews with patients' carers who had been interviewed at Time A. The relationships between the carers who were interviewed and the people for whom they provided care were as follows:

13	wives, caring for their husbands
3	husbands, caring for their wives
6	daughters, caring for their mothers
1	daughter, caring for her father
1	sister, caring for her brother
1	son, caring for his mother
1	male friend, caring for woman in whose house he had been a lodger for 20 years
1	a warden, providing support for a man who lived in sheltered accommodation and attended CREST

When CREST was originally conceived it had been argued that a night sitter service in the patient's home was not always the most appropriate way of relieving carers. When people with dementia suffer from sleep disturbance and restlessness, their living accommodation needs to be large enough for a night sitter to be with the patient and leave carers enough space to spend some time uninterrupted. The type of accommodation carers and CREST patients lived in and the number of people in each household was identified (Appendix 9.1). The majority of carers lived alone with the person with whom they cared in small flats or houses.

The warden who was supporting a male patient did not wish to complete the carer sections of the Crichton Visual Analogue Scale or to be interviewed about the effects of the patient's attendance at CREST. Therefore, twenty six carers completed the Crichton sub-scales on their ability to cope with and their level of anxiety about the relative or friend who attended CREST (Appendix 9.2). Their median score on the Coping sub-scale at Time A was 47.5 (range 10-86). Thirteen of the 26 carers gave middle of the range coping scores (40-60) leaving seven who indicated that they coped well (0-40) and six that they had difficulty in coping (60-100). The median score on carers' anxiety at Time A was 75.5 (range 14 to 95). Eighteen of the 26 carers indicated a high level of anxiety (73-95) and most were very anxious when the patient was first admitted. However, by encouraging the patients' attendance at CREST, the carers had recognised that they could not provide all the care their relative/friend required. Therefore the mid ratings on the Coping sub-scale indicate that although the carers required assistance the majority still felt able to cope to some degree. The fact that carers encouraged patients' attendance at CREST can be interpreted as a coping mechanism in that these carers acknowledged not only their need for assistance but were also prepared to accept help from the statutory services.

9.2 Results from patients' and carers' ratings on the Crichton Visual Analogue Scale

9.2.1 Carers' and nurses' Crichton Visual Analogue Scale ratings of patients

Wilcoxon Matched Pairs Signed Ranks Test was used to test the hypothesis that:-

> "There is no significant difference between patients' scores using the Crichton Visual Analogue Scale when rated by nurses and carers."

Comparisons of ratings at Time A, B, C and D (Appendices 8.4 and 8.5) showed a significant difference between nurses' and carers' ratings on all four occasions ($p < 0.01$) (Table 9.1). The carers consistently rated patients as more dependent than did the primary nurses (Chapter 8, Tables 8.8 and 8.9).

PERIODS OF COMPARISON	NUMBER OF PAIRED CASES	WILCOXON T STATISTIC	P VALUE
Time A	25	57	<0.01
Time B	16	1	<0.01
Time C	15	9	<0.01
Time D	9	1	<0.01

Table 9.1 Comparison of nurses' and carers' Crichton Visual Analogue Scale ratings of patients at Times A, B, C and D

The correlation co-efficients using Spearman's rho between patients' ratings made by nurses and carers for each time period showed a moderate to high positive association for each period:

Time A	$n=25$	r_s 0.46	$p < 0.05$
Time B	$n=16$	r_s 0.71	$p < 0.001$

Time C	n=15	r_s 0.53	$p < 0.05$
Time D	n=9	r_s 0.81	$p < 0.01$

To identify whether the increase in the size of the correlation between Time A and Time D could be associated with nurses and carers working together in partnership, coefficients were calculated for the sub group of patients at Time A who were also rated at Times B, C and D (Table 9.2 and Appendix 9.3).

SUB GROUP AT TIME A ALSO RATED AT TIMES B, p1724Yn=15 C AND D	SPEARMAN'S RHO	P
n=16		
Rated at Time A	0.66	<0.02
Rated at Time B	0.71	<0.001
Rated at Time A	0.48	<0.05
Rated at Time C	0.53	<0.05
n=9		
Rated at Time A	0.53	ns
Rated at Time D	0.82	<0.02

(ns = not significant)

Table 9.2 Carers' and nurses' ratings of the patient sub-group rated at Time A and Times B, C and D

This showed that a significant positive correlation between nurses, and carers, ratings increased over the six month period of patient attendance at CREST (Table 9.2). The substantial increase in the co-efficient between Time A (r_s 0.53) and Time D (r_s 0.82) indicates that nurses' and carers' perceptions of patients converged over six month periods of patient attendance at CREST. The sample size of nine at Time D is too small to draw firm conclusions; although it does suggest that carers and nurses may have been working closely together and exchanging information about patients, although, even at Time D, carers continued to rate patients as having greater problems with sleeping and incontinence than did nurses (Tables 8.8 and 8.9). Possible reasons for the disparity in sleeping scores as rated by carers and nurses are discussed in Chapter 8, Section 8.5.1. On the Continence sub-scale the medians for nurses ranged from 27.5 to 46.0 and for carers from 50.0 to 88.5. Nursing staff instigated continence management programmes for some patients, which reduced the frequency of incontinence. For example when a nurse observed a patient being restless at 2.00 a.m., if appropriate the patient was taken to the toilet. The same patient's carer might be asleep when the patient became restless and not awaken until the patient had been incontinent. Therefore, the carer would rate the patient as "frequently wet" while the nurse would record an improvement in the patient's ability to remain continent.

CREST nursing staff had sufficient time and energy to implement nursing actions to promote patients' sleep and prevent incontinence. Nurses then rated patients as more independent than did carers. The higher scores rated by carers on the Sleep and Continence sub-scales were probably associated with carers' difficulties in coping with a relative or friend who was incontinent or had a disturbed sleep pattern (Gilleard, 1984; Mace et al, 1985; Sanford, 1975).

9.2.2 Carer Crichton Visual Analogue sub-scales: anxiety and coping

Carers completed two sections of the Crichton Visual Analogue Scale to indicate their levels of anxiety about and ability to cope with their relative or friend who suffered dementia. Wilcoxon Matched Pairs Signed Ranks Test was used to test the hypothesis that:

> "There is no significant difference in carers' self ratings on the Crichton Visual Analogue sub-scales anxiety and ability to cope at Times A, B, C and D."

Carer ratings on both the Anxiety and Coping sub-scales were compared between Time A and B, A and C, A and D, B and C, B and D and C and D (Appendix 9.2). No significant differences were found (Table 9.3a and 9.3b).

CARERS' RATINGS PERIODS OF COMPARISON	**NUMBER OF PAIRED CASES**	**WILCOXON T STATISTIC**	**P**
Time A with Time B	18	75.5	ns
Time A with Time C	16	53.5	ns
Time A with Time D	10	24.0	ns
Time B with Time C	14	46.5	ns
Time B with Time D	8	7.0	ns
Time C with Time D	9	13.0	ns

Table 9.3a Comparison of carers' ratings of anxiety on the Crichton Visual Analogue Scale

CARERS RATINGS PERIODS OF COMPARISON	NUMBER OF PAIRED CASES	WILCOXON T STATISTIC	P
Time A with Time B	18	66.5	ns
Time A with Time C	16	47.0	ns
Time A with Time D	10	15.0	ns
Time B with Time C	14	48.5	ns
Time B with Time D	8	14.0	ns
Time C with Time D	9	14.0	ns

Table 9.3b Comparison of carers' ratings of coping on the Crichton Visual Analogue Scale

In order to determine whether carer anxiety and coping scores at Time A (n=26) were associated with patient outcome, Kruskal-Wallis analysis of variance of ranks was used to compare the data against four patient outcome groups; death (n=7), admission to long term care (n=10), discharge home (n=6) and registered at CREST for more than one year (n=3). No significant differences between the four groups was found when compared to carers' coping rating at Time A (H=0.73, df=3, ns) and their anxiety rating at Time A (H=2.97, df=93, ns). It is concluded that carer self ratings are not predictive of patient outcome.

9.3 Carers' feelings concerning patients' attendance at CREST and changes to carers' lifestyles

Although carers were asked two separate questions concerning their feelings about patients' attendance at CREST and changes to their own lifestyles associated with dementia sufferers' use of CREST, their responses overlapped. The information obtained from carers' reponses to the two questions is presented separately for Time A (within one week of patient admission) to illustrate differences and similarities. Subsequently, the responses have been collated for Times B, C and D to avoid repetition and to indicate the themes which emerged from the information obtained.

9.3.1 Question 1, Time A

Twenty six carers were interviewed at this time within one week of their relative or friend's first attendance at CREST. Presented here are the responses of carers to question 1:

1a) Can you describe the feelings you have experienced concerning your relative/friend's attendance at the night hospital?

1b) Have you any ideas why you feel the way you do?

Positive responses

Twenty two carers expressed positive feelings about their relative or friend attending CREST. Eight carers said they felt "relief" and seven were either happy or pleased. Other positive feelings included feeling "brilliant" and "comforted". The main reasons given were:

		Number Responding
a)	Increased sleep for carers	4
b)	More rest for carers	10
c)	Peace at home for carer and family	2
d)	Relaxation for carer because they knew patient was being well cared for	1
e)	Reduction in working	1
f)	Received real help for first time	1
g)	Having help with care	3

h)	Having better night's sleep because patients slept better at home when not at CREST	2

(Some carers gave more than one reason)

Individual vignettes are presented to illustrate carers' responses in more detail. The responses are grouped into four categories according to the relationship of each carer to the person for whom they provided support. The categories of carer are wives, husbands, daughters and other carers.

Wife carers

Wife caring for Mr H.T.

> "Relief! I felt a bit strange the first night. I put my hand out, and he wasn't there, it was a bit confusing."

The reasons she gave for feeling like this were:

> "I know he is in safe hands, and although we have never been separated before, I have accepted it. We have been married for 47 years and you don't think of the day that you will be separated. Even for a short while. He can't converse very much, but when I ask him he said he loves me and CREST. I think he is also doing it for me because he knows how much a night's rest will help me."

Mrs H.T. was motivated to care for her husband by their mutual attachment. She asked her husband if he loved her, and in turn he affirmed his love and commitment to her. By seeking positive feedback from her husband she identified reciprocity in their relationship and a motive for continuing to provide his care despite his increasing disability. Mr H.T. was admitted to hospital following deterioration in his condition during the tenth week of his CREST attendance. He died in hospital four weeks later without returning home.

Wife caring for Mr J.F.

> "I feel good because I know he is being well cared for. I felt a little strange the first few nights he went but I have no regrets. My son agrees with me. Sometimes I say, 'what have I done to deserve this?'. He has Parkinson's Disease you know."

The reasons she gave for feeling like this were:

> "I am old myself, and not too long ago I had an operation. My doctor told me not to lift anything, I have done so well up to now. Still it was easy because I love him. He didn't always used to be like that. He loves going to CREST. Come 7.30 p.m. he starts getting ready. He says he has made friends there. I am so happy for him. When he goes I watch the 10 o'clock news and then I go to bed. The other day I had a long bath after he left, the first one for so long."

This response illustrates the wife's emotional commitment to her husband. He was discharged home at his wife's request following improvement in his condition. The break his wife had from both his attendance at CREST and in-patient admission for treatment appeared to be enough for her to continue in her role as carer.

Wife caring for Mr C.L.

> "Relief, I know I'm not going to be called to get him something."

The reasons she gave for feeling like this were:

> "Can you understand what a relief it is to be able to go to bed and to know someone else is caring for him? If he falls, if he disconnects his leg bag and floods the place the nurses will be there to cope and they won't get cross with him. You see recently he does the opposite to what I say. Although usually he's so good, he knows he gives me a lot of work. I need a break. I go out for five minutes with the dog and when I come back he's usually on the floor. I know he's not very happy going out at night and it does worry me but I need a break."

Mrs C.L. indicated the physical and mental burden that was resulting from caring for her husband which sometimes results in her getting cross with him. She acknowledged that her husband did not particularly enjoy going out to CREST but that her need for a break outweighed his reluctance. She inferred that without help she would not be able to continue to cope with caring. Her answer did not indicate an emotional attachment to her husband as did the other two wives' responses in this section. When the relationship between carer and the person cared for deteriorated, and the carer cannot perceive any benefits from caring, this is often the point at which carers wish to relinquish their role (Bergmann et al, 1983). In fact, Mrs C.L. requested residential care for her husband after he had attended CREST for 15 weeks. He was admitted to a nursing home 19 weeks after initial CREST attendance.

Husband carers

Husband caring for Mrs G.B.

> "It felt strange the first few nights, I would wake up looking for her. Now it is getting better. I am pleased about the night hospital. I only wished I knew about it before. I heard it from the day hospital. I am not concerned. I knew no harm will come of her. The staff seemed to be nice."

The reasons he gave for feeling like this were:-

> "I get some sleep now, makes me feel better during the day. She doesn't mind going, she has never said no or appeared to be sad. Anyway I don't think she knows what is happening or where she is. Usually she will do what I say. She doesn't talk about CREST but I know it is fine. I think though, she recognises me and misses me if I am not with her. Well, it cannot be helped. When they come to collect her, she wants me to go with her. I can understand that, we have been together for 40 years. I have to do my best by her now that she needs me. I took my vows and said for better or for worse, in sickness and in health. I know if I were sick she would have looked after me."

Mr G.B. clearly remained emotionally attached to his wife and found reward from caring for her. He thought that his wife recognised and missed him which may have been one reason for his continuing to care for her. His marriage vows were also a motivator, as was the fact that he believed that she would have done the same for him in the circumstances. Mrs G.B. was admitted to hospital in week 38 of her registration at CREST and died without returning home a week later.

Daughter carers

Daughter caring for Mrs M.L.

> "I was a bit nervous at first. I didn't know how she was going to react. I have always worried about my mother. The first night she went, she got very distressed but after Robert, Anna and the other girl spoke to my mother and us (me and my husband) they made it all so natural. I feel fine now and my mother has settled and likes it."

The reasons she gave for feeling like this were:

> "I was getting tired and worked up. I was getting no rest at all, and my nerves were giving way. I got to the point where I couldn't hold my temper and sometimes I was unfair to my mother. My doctor said if I didn't get a break, a rest, or a holiday, I will have a nervous breakdown. I am very happy now and pleased she is going to the night hospital. It is comforting to know that there is someone there who cares. They had some problems in the beginning with the low beds, mum is a big woman but now they have got new beds. It is much better. I don't live very far from the hospital, the staff said if anything happens, it doesn't matter what time it is, they will contact me."

Mrs M.L. was 91 years old and her daughter was in her sixties. Clearly Mrs M.L.'s daughter was exhausted by the burden of caring for her mother. She had begun to be "unfair" to her mother because she could not hold her temper. Despite her exhaustion she was concerned for her mother's care at CREST and comforted because she believed the staff cared for her mother. Her mother's health deteriorated and she was admitted to respite care 13 weeks after first attending CREST. Her daughter felt unable to have her mother home again and Mrs M.L. was transferred to long stay facilities within the hospital.

Daughter caring for Mrs L.A.

> "I feel alright - it's brilliant. I get to sleep for four nights apart from my young children who occasionally get me up for various reasons. Mother is blind and doesn't like moving about much and of course the young kids are very noisy especially when home from school."

The reasons she gave for feeling like this were:

> "It's an enormous relief. I can concentrate on the kids more in the mornings and get them out to school and nurseries and because mother is also diabetic I was unable to give her meals regularly so she has meals on wheels. I am relieved someone else (CREST, I mean) are helping with mother's care - she has a wash and her breakfast before coming home in the morning."

Mrs L.A.'s daughter illustrated the problems of being one of the 'women in the middle' (Brody, 1987); of caring for two generations, both children and a parent. Although Mrs L.A. was getting help with her mother it only gave her relief from one part of her caring role - relieving her to undertake another demanding role more competently. Mrs L.A. was admitted to residential respite care during weeks eight and 15 of her registration at CREST because her carer was ill. When her carer was better Mrs L.A. was discharged home from respite care and her daughter requested that she be discharged from CREST. Her daughter stressed that her mother may return to CREST if she, the daughter, needed help at night in the future.

Other carers

Sister caring for Mr B.H.

> "I feel very privileged to participate. I feel it is a wonderful scheme which is equally beneficial to me and my brother. I am sure he will benefit eventually. He's so very confused at present. He doesn't sleep. He didn't know where he was going. The nurses were wonderful, so kind to him."

The reasons she gave for feeling like this were:

> "He is in safe care and I can shed some of the worry about him for part of the day. I felt as I was recovering from a long illness, I got into bed and slept, a really natural refreshing sleep instead of wakening every few hours and listening for him making noises."

Mr B.H.'s sister managed to provide care at home for her brother until he died. She originally asked for him to attend CREST because she had been ill. He then had a period of six weeks respite care while she had an operation. When she was better he returned home and re-commenced attendance at CREST.

Negative responses

Six carers expressed negative feelings (two of whom also reported positive feelings) about their relative or friend attending CREST. These fell into two categories:

Unhappy	1
Guilty	5

All the carers who said that they felt guilty were female and gave different reasons for this feeling:-

a) they could no longer cope alone
b) the patient had not wanted to go
c) they felt relieved
d) they felt they had deserted their relative/friend.

The following vignettes illustrate carers' feelings in more detail.

Wife carers

The carer who felt unhappy was the wife of Mr F.B. Her reason primarily involved the fact that they were a devoted couple and had never really been apart in 52 years of marriage:

Wife caring for Mr F.B.

> "I was very unhappy, I did not like the idea of being apart. I felt devastated as if the world had come to an end. It felt as if we parted for ever when the ambulance came and he went, I walked up and down aimlessly doing nothing, just thinking, thinking and crying. We have been married for 52 years and this is the first time we have been apart."

The reasons she gave for feeling like this were:

> "We are devoted to each other. We both feel the need to go through good and bad times together."

Mrs F.B. missed her husband dreadfully and sent him to CREST at great personal cost. He attended for six weeks and was then admitted to hospital for treatment. He returned home after a short stay and then went into hospital again. He died eleven weeks after first attendance at CREST.

Wife caring for Mr N.B.

> "I felt he didn't want to go on the first night, he never leaves my side during the day, he's like my shadow. I am never alone, I went with him to the night hospital and I couldn't get away, he kept holding onto me, I knew he wouldn't stay. I felt so guilty leaving him."

The reasons she gave for feeling like this were:

> "I knew he would be difficult, it was terrible, it worried me sick, he was hanging onto me. I couldn't get away, he was in this big room on his own and I knew if he got out of bed on his own he would not have anything near to grab or hold onto and he would fall and break his leg. I was so worried I left him at 11 o'clock at night I was so upset it broke my heart, I stayed awake. It was so awful he's worse now."

Mrs N.B.'s interview took place the day after his attendance at CREST. She was the carer who expressed most distress at leaving her husband. Mr N.B. did not attend CREST again. He was admitted to long term care, presumably at great personal cost to his wife.

Wife caring for Mr M.S.

> "Guilty. I never thought I would miss him but I did. When he left I sat down and I thought, why did he have to go, but then I thought neither of us had a choice. Now I think it was and is the best thing that happened to both of us. Going to CREST is a great comfort."

The reasons she gave for feeling like this were:

> "I felt he should be in his home and in his own bed. Maybe if I had an extra room he wouldn't have had to go. I can still be close to him during the day, he likes it."

Although Mr M.S.'s carer reported feeling guilty about sending her husband to CREST she also felt comforted. This ambivalence with regard to accepting help has been reported in other studies (Bergmann et al, 1978; Levin et al, 1989). She was the only carer who suggested that had she had bigger living accommodation a service at home may have been preferable. Mr M.S. was discharged home at his wife's request after 21 weeks of attendance at CREST.

Daughter carers

Daughter caring for Mr J.V.

> "I felt guilty, it was as if I was throwing him out of his house. The first night he went to CREST I did not sleep, I stayed awake and kept on listening for his calls. Once I heard him calling out "mother, mother, won't you help me?" I went and, of course, he wasn't there. The second night I accepted it and slept. You see, when he doesn't get his way, he says, "why don't you put me down for good." That hurts me."

The reasons she gave for feeling like this were:

> "I looked after him for a long time, I suppose it is like having a baby to care for, and although I felt guilty I realised I had to let him go. They are nice people there who can give him more attention than I can, especially in the morning, they wash him properly and shave him. To have a wash at home it is like a big operation, it needs planning, he is confined to a wheelchair, can't stand nor walk, the wheelchair won't go in the bathroom so I wash him in the kitchen. It takes us half a day to complete the job."

Miss J.V. described the burden of caring for her father and the advantages of CREST. She was clearly emotionally attached to her father in that he could and did hurt her with words. She was an unmarried daughter who felt she was throwing her father out of "his" home. Carers who are residing in parental acommodation often feel compelled to continue caring because they have no where else to go (Finch and Groves, 1983). This may have applied to Miss J.V., who described how close she was to hitting her father in response to question 2 (Section 9.3.2).

Daughter caring for Mrs V.H.

> "I don't particularly want my mother to go in fact I felt guilty but for my husband's and my own sake it's best. I was getting desperate at night as I was getting up every hour some nights and my husband is a prison governor who has a stressful job and although he is a wonderful man, he has to get up at 5.30 a.m. and he was not getting sleep. CREST was our lifeline."

The reasons she gave for feeling like this were:

> "I was getting desperate. I was bad tempered and tearful as mother became more restless at night. I knew she couldn't help it but she kept calling for me even when I was beside her bed."

Mrs V.H.'s daughter also reported feeling guilty about sending her mother to CREST. She was adamant, however, that her husband needed more sleep and was prepared to send her mother to give him and herself a break.

9.3.2 Question 2, Time A

In response to question 2:

2a) Has the fact that your relative/friend comes to the night hospital changed your day to day life? YES/NO

2b) If YES, please describe the change.

At Time A twenty one carers (n=26) reported that there had been changes in their lifestyle and five reported no change. Figure 9.1 indicates the changes carers reported.

CHANGES	NO. OF CARERS REPORTING CHANGE
Good night's sleep	19
Feeling better themselves	15
Time for themselves	14
Time for housework, including cooking	10
Feeling more able to cope generally	10
Feeling more relaxed	9
Reduction in physical caring tasks	6
Reduction in family disruptions	5
Feeling less anxious/tense	3
Cry less	3
Time for socialising	3
Time for shopping	2
Changed outlook for the future in a positive way	2
Time for employment	1

Figure 9.1 Changes to carers' lifestyle as a result of their relative/friend's attendance at CREST at Time A

Carers described both changes in the way they spent periods of time and in their feelings associated with CREST.

The following comments were made by wives of CREST patients.

Wife 1

> "Absolutely, instead of dreading the day, I look forward to it now, I am not so tensed up. I can concentrate and get things done. I can wash and cook at night after my husband has gone, I am so much better."

Wife 2

> "I feel better, I can go to bed early, or I can watch T.V. for a while and my neighbour can drop in for a chat or I can go to her."

Wife 3

> "It gives me a clear day because he attends the night hospital Wednesday night then he stays in the day hospital on Thursday and comes home in the evening. For one morning I haven't got to get him up and dress him, it is a struggle. Staying for the day hospital means that I can go shopping without having him on my mind. When he is collected in the evening I go straight to bed and have a good night's sleep."

Wife 4

> "I am able to start reading again, I love reading, see all the books there stacked up, the mobile library calls once a month. I have only this week lifted a book. I have started cooking a little bit more now. My husband comes home, he is dressed, washed and has had his breakfast. Oh, I hope it lasts."

The following were made by husbands of CREST patients.

Husband 1

> "When she is away at night and I can get to sleep, I can look after her better during the day. I am very tired myself but

> when I sleep at night I can get up at a regular time instead of trying to catch a few minutes here and there during the day."

Husband 2

> "When she goes to the night hospital I see the news on television and then go to sleep. The following day you would be surprised how different I feel, usually I would be falling asleep here in the sitting room next to her and if she moves I jump. Now I don't need to do that, or at least not so often. I am, however, still very worried about the future."

The following were made by daughters of CREST patients.

Daughter 1

> "She has only been for three nights so far but it is a God-sent service. My husband and I can feel the difference in ourselves. We are more relaxed and more pleasant with each other, we feel stronger and get on with our jobs better. My husband says that he felt the difference in himself after a good night's sleep. He can work in the garden all day."

Daughter 2

> "I have been able to sleep soundly and I didn't have all the washing to do when I got up because he usually had a wet bed. I don't have to try and get enough linen dry. He comes home dry and he is already washed and bathed. This gives me a real break."

Daughter 3

> "I can get into the bath in the morning and have a soak, wash my hair. I usually can't be bothered."

Daughter 4

> "My husband and I both sleep well when mum goes to CREST and we have a few hours on our own in the evening to just sit and talk without mum wanting to know what we are saying. In the morning I get up, go to the bathroom, no rush or interruptions, put the kettle on have a cup of tea, it is so nice. Please don't get me wrong we love mum a lot. When mum comes home in the morning she has had breakfast and I try to

> sit and have a chat. I am less bad tempered, less tearful and things are easier to cope with."

The following comment was made by a friend of a CREST patient.

> "You have little time to yourself, I clean the house, I catch up on my sleep. Later on I might even go out and have a drink with friends. For the time being it is sleep I want."

9.3.3 Questions 1 and 2, Time B

Eighteen of the 26 carers interviewed at Time A were re-interviewed at Time B, six weeks after their relative/friend's first attendance at CREST. The group of carers interviewed was made up of:

9	wives caring for their husbands
1	husband caring for his wife
5	daughters caring for their mothers
1	daughter caring for her father
1	sister
1	male friend

All 18 carers expressed positive feelings regarding their relative/friend attending CREST; the feelings described were similar to those at Time A, with two carers expressing a reduction in feelings of guilt about using the service. Reasons given for these feelings reflected those given previously. One carer said that she "frankly couldn't cope anymore without CREST", demonstrating a reliance on the service which she had not expressed at the first interview.

Fourteen carers reported that there had been a change in their day to day lifestyle. The breakdown of day to day life changes was similar to those given at the first interview with improvements in carers' ability to have a proper sleep and feeling better in themselves being predominant (Figure 9.2).

Two carers illustrated the positive advantages of CREST to them, saying:

> "Before I was feeling that I wanted to scream, now these feelings are a thing of the past."

> "Well of course when I sleep at night I can cope better during the day."

CHANGES	NOS. OF CARERS REPORTING CHANGE
Improvement in sleep	12
Coping/feeling much better in themselves	9
A more normal life	6
Visiting or receiving visitors	6
Able to watch television uninterrupted	6
Reduction in physical caring tasks	6
Time for themselves	5
Fewer family arguments	3
Less depressed/anxious	3
Feeling more relaxed	2

Figure 9.2 Changes to carers' lifestyle relating to their relative/friend's attendance at CREST at Time B

A wife carer said that her husband's attendance at CREST had not changed her day to day life but that she felt her burden was lighter, while a daughter carer reported:

> "Well I have to get up early to get my kids to school anyway so I rarely have a minute to myself. Of course, I have mum here all day."

The daughter who cared for her father reported that her day to day life had not changed, because he had only attended for two nights and then stopped. She expressed her frustration at her situation, saying:

> "Sometimes I sit on my bed at night and cry. I feel I want to hit him and I am so ashamed of it. I feel so guilty. The other day I nearly hit him. My hand stretched out towards him, I stopped myself in time, I embraced him instead and cried. He must go back to CREST, it is for the best for him and for me."

This patient did return to CREST.

9.3.4 Questions 1 and 2, Time C

Sixteen carers were interviewed at Time C three months after their relative/friends' first attendance at CREST. The group interviewed differed from Time B, in that four carers who had been interviewed at that time (the sister looking after her brother, two wives caring for their husbands and one daughter caring for her mother) were not interviewed because their relatives had either died or had been discharged from CREST. Two carers who were interviewed at Time A were re-interviewed at Time C. They were a husband caring for his wife and a daughter supporting her mother. Neither of these carers were interviewed at Time B, the husband carer because he declined and the daughter because she had been ill in hospital and her mother was in respite care at that time.

The majority of carers' responses were similar to those given previously. However, one carer was "afraid" of her relative who had recently scratched her badly. This carer expressed reservations about CREST, suggesting that perhaps her relative needed in-patient care. A wife caring for her husband said:

> "I don't know how I would cope if I had to do what I used to do before, it bears no thinking".

Her reasons for these feelings were that she felt she should be able to get more in-patient respite care for her husband than she was receiving at that time. It appeared that this carer was beginning to seek help over and above that which she was being offered at CREST. Only one carer, a wife, attributed a positive change in a patient's sleep pattern to attendance at CREST:

> "Since going to CREST he appears now to be more settled at night at home. I sleep for longer periods but if I hear a sound I quickly wake up. I think meeting people is good for him and he seems happy going there."

All 16 reported changes to their day to day lives. Fifteen said they regularly had a good night's sleep and 12 felt more relaxed and less anxious in themselves as a result of the patient's attendance at CREST. Eight carers said they had more time for housework and eight time to socialise with friends both in and outside their homes. Three reported using spare time for shopping and one carer, a daughter, had sufficient time for employment and was working in a public house one evening a week. Four carers reported that their families were less disrupted, while eight said that they were better able to cope with life. A common theme that emerged was that carers felt better able to cope with the people for whom they cared and as a result were nicer to them than before the patient's CREST attendance. One carer illustrated this by reporting:

> "I don't shout at her so much and I think I look after her better now she goes to CREST."

9.3.5 Questions 1 and 2, Time D

Ten carers were re-interviewed at Time D six months after their relative/friend's first attendance at CREST. The group consisted of:

4	wives caring for their husbands
1	husband caring for his wife
3	daughters caring for their mothers
1	daughter caring for her father
1	male friend

Three carers reported very similar feelings when interviewed at Time D to those they expressed at Time A. Six carers: three wives, two daughters and a male friend, were more ambivalent than on previous occasions for a number of reasons and one husband was more positive; their responses are presented.

Wife carers

Wife caring for Mr T.D.

Time A

> "I am very pleased. They are very kind and nice, it is a good idea. I think a lot of him and I miss him a bit, naturally, but I am glad that he is there."

The reasons she gave for feeling like this were:

> "It gives me a rest, daytime I can cope more, I used to go out before he became ill, now I can't. As they get older they get the better of you, don't they? He is well cared for there, they even bathed him this morning, he was spotless when he came home. Sometimes he would get up in the night and empty all the clothes out of the wardrobe on the floor. A few times he fell, I couldn't lift him up. Now I only have to cope for three nights."

Time D

> "I felt alright about him going. I think I wasn't sure, but it broke his heart, he didn't like it at all. He used to cry and he made me not want him to go. I couldn't let him go any more, they were very nice to him there, but it's better in your own house.

The reasons she gave for feeling like this were:

> "I get very anxious and nervy, he made me feel so bad that I was doing wrong. He used to look at me and I knew he was cross and I get upset, you see I never went out much, we were always together, I can't go out on my own, I have been looking after him now for several years."

Mr T.D. had been attending spasmodically between weeks 13 and 26 after a period of residential respite care in weeks eight to 13. Although his wife had valued CREST when interviewed at Time A, by Time D she acknowledged that he had really ceased attending with her blessing. The benefits of her husband's attendance reported at Time A were clearly outweighed by her husbands' crying when going to CREST. Mrs T.D. was motivated to go on caring for her husband and because she did not go out alone when her husband was at CREST felt it was kinder to keep him at home.

Wife caring for Mr B.G.

Time A

> "I was so delighted to hear about the night hospital and accepted immediately as I was so depressed and not coping - felt so ill. This has helped me so much - I got my night's sleep, its marvellous - life is so much better. I almost had given up."

The reasons she gave for feeling like this were:

> "I feel my husband is safe and very well looked after and it's so wonderful for me to have a nights sleep. My husband comes home washed and dressed and has had his breakfast. I can have a bath at night and relax."

Time D

> "I am happy and couldn't survive without CREST but I just seem to sit waiting for the doorbell to ring. It's later and later now when he is collected and he gets so very restless, 9.30 p.m. last night. I am so exhausted by the time he actually goes, the ambulance didn't take him to the Whittington day centre today because they came before he was home from CREST."

The reasons she gave for feeling like this were:

> "I seem to be more tired now every week that goes by because during the day I am with him all the time, he is much more mobile - constantly getting up from the chair and wanting to go downstairs and out onto the street. So I have to leave my work until he goes at night - I have to get dinners ready in advance, I daren't leave him in case he falls and breaks his leg. I couldn't manage to lift him if he did fall; he should have gone in for two weeks respite this week but the sister rang up and said he couldn't come until next week and then only for one week instead of two."

The difference between Mrs B.G.'s responses to this question at Time A and D is marked. At Time A she emphasised the advantages of CREST to herself. At Time D she has begun to wait for her husband to leave, to give her a break. Her second response described her caring role from an instrumental perspective. There is no indication of any emotional attachment to her husband at Time D; although this was not explicit at Time A, the reference to his safety and the quality of care he received at CREST was an indication of concern. The health care system was not sufficiently well co-ordinated in assisting this carer to look after her husband at home. The ambulance collection and delivery times resulted in Mr B.G. missing day care, and respite care had been postponed. Mr B.G. was admitted to long term care 44 weeks after his first attendance at CREST. His admission was arranged at the request of his wife who no longer felt able to continue supporting him at home.

Wife caring for Mr S.B.

Time A

> "Relieved to get the break and for him to go."

The reasons she gave for feeling like this were:

> "I still wake up in the night to see he wasn't there. I had to think where he was, but I soon got back to sleep. Oh, he's a real handful now, I am getting near breaking point myself. I went to hit him the other day, he fell and I couldn't get him up. I felt so guilty about it - I never did anything like it before. He's been a great husband to me."

Time D

> "CREST has been great for me to get a break - but he has had flu for the past few weeks, he has been very ill in hospital and they didn't feed him there, left his meals in front of him. I had to go and feed him so I am keeping him at home until he is stronger."

The reasons she gave for feeling like this were:

> "I think my husband got pneumonia before Christmas due to going out in the cold at night and changing environment/atmosphere/temperature. I can't risk this happening to him again because when he is in hospital he gets worse and I got even more tired going up and down visiting him. I even have to walk him around there otherwise he would be left in his wheelchair. He is much more dependent now. I won't let him go to the night hospital until the weather is better."

The change in Mrs S.B. responses between Time A and Time D appears to be attributable to the deterioration in her husband's condition. She thought that his pneumonia may have developed because she sent him out into the cold. That she remained fond of him is clear from her reference to the fact that she needed to "feed him" and keep him at home until he was stronger. As a result of his deterioration Mr S.B. appears to be easier for Mrs S.B. to care for than when he was well enough to be "a real handful" at Time A. His deterioration over the six month period between Time A and Time D is consistent with a diagnosis of Alzheimer's disease (Lishman, 1987). When people with Alzheimer's disease become less mobile and more physically dependent they are often easier to care for than in the earlier stages of the disease process, when behavioural problems are paramount. Mr S.B. was eventually discharged home from CREST when he became too frail to attend. A night sitter service was arranged.

<u>Daughter carers</u>

Daughter caring for Mrs M.B.

<u>Time A</u>

> "I feel wonderful, I never had any fears or apprehensions, I know the hospital. I did not know how to break the news to my mother, so I told her at the last minute, anyway she is so confused she doesn't understand what is happening."

The reasons she gave for feeling like this were:

> "For the first time I received some real help, I can now sleep at night and all night. When she leaves for the hospital I sit down for a couple of hours to unwind after the days work. I go to bed at about 10 p.m.. When you are on your feet all day long, your muscles hurt and your head is heavy. I need some time to relax before I go to bed. I look forward so much to her going to CREST, and not having to worry. Looking after her is not for a day or a month, it is year after year, there comes a time that you body gets tired, I am an old age pensioner myself. The night hospital has been a big tonic to me. I hope it will go on for ever, not just for me but for all people in my situation."

<u>Time D</u>

> "I am quite content when mother goes to the night hospital as I can have a good nights sleep. She is well looked after there, I don't let her go if she's very noisy and confused as she just calls out in her own language (Italian) all the time and although she is 94 years old she calls for her mother loudly and non stop.

The reasons she gave for feeling like this were:

> "I just had her home from two weeks respite care and now she has all the skin broken on her bottom. She never had that before and she was in enough pain before. I know that nurses can't help it but I have to do it all on my own at home. I

> told the district nurse I met at the carer's group so she is coming in to see what treatment is necessary. CREST is so good but they are short of nurses too and sometimes they have no ambulance, but CREST is very very good for me to sleep."

Although Miss M.B. still appreciates CREST at Time D her enthusiasm is less marked than at Time A. Her mother had developed a pressure sore while in respite care; although she excuses the nursing staff, she also indicates that all the time she has cared for her mother this had never happened. The benefits of her mother attending CREST are still clear to her daughter who can get some sleep as a result. Miss M.B. implies that CREST is the lesser of two evils, when compared to respite care. She is still emotionally attached to her mother, keeping her at home when she is very confused to prevent further distress, and is very concerned that her mother's physical pain (due to arthritis) may be worse following the development of the pressure sore. Miss M.B. cared for her mother at home, with district nursing and CREST nursing support until she died.

Daughter caring for Mrs V.H.

At Time A Mrs V.H.'s daughter had felt guilty about her mother's attendance at CREST. Despite these feelings she reported advantages of CREST. When interviewed at Time D her response was:

> "Well, CREST saved our marriage, my husband's job was beginning to suffer. Mum just had us on the go all night calling out, wandering, our life was hell. We heard about CREST, it has been marvellous. Having said that I hated to see her going out at night in the winter when it was dark, wet and cold but it was great to know she was going to be cared for by such caring and devoted nurses in CREST. I did feel guilty for a long time but now mum will be going into long term care."

This carer had ceased to feel guilty about her mother's attendance at CREST. This change in the carer's feelings appeared to be related to the improvement in both herself and her husband's lifestyle associated with her mother's use of CREST. Six months after her mother's first attendance at CREST Mrs V.H.'s daughter had decided to arrange for her mother to go into long term care. The disadvantages of caring for her mother at home, even with the support of CREST outweighed the advantages. It appears that once this carer had accepted assistance with her mother she felt able to relinquish the role, in favour of preserving a better life for both her husband and herself.

Other carers

Male friend caring for Mrs G.N.

Time A

> "I feel it is good for her and me. I can get to sleep and feel better during the day. It is a very good scheme, it gives carers a break. I can now go to bed knowing that I won't be woken up. I haven't experienced this feeling for a long time."

The reasons he gave for feeling like this were:

> "She is fine there. I examined the place myself. The toilets, the bathroom, the lot, it is so clean and spotless. They take her and bring her back, it is so easy. Many times I slept half an hour for the whole night."

Time D

> "I felt all along that it was the best thing that happened to me but you know she used to go for four nights a week, now she goes for only two and even then she doesn't want to go. I have great difficulty in trying to persuade her to go. I keep on telling her that it is for the good of both of us that she must go. She says she doesn't want to leave the house and she can cope by herself."

The reasons he gave for feeling like this were:

> "I can't help worrying. If she doesn't go to CREST I fear I would be too tired to look after her during the day. I would start sleeping on the armchair in the kitchen again because I can't stay awake all day not having slept during the night. Even if I go to the toilet I am worried in case she needs something while I am there. The pressure is building up, I went to see my doctor the other day and although my blood pressure is alright for now, I know soon it won't be. You have to look for preventing things don't you? But she doesn't understand she doesn't know how much I do for her. Still I think she will go to CREST, she says, she won't now but when the time comes she will go."

This carer wants his friend, Mrs G.N., to attend CREST but she is increasingly reluctant to attend. He anticipates Mrs G.N.'s future care requirements and tries to make plans to ensure that this will be available. This responsibility was described as anticipatory care by Bowers (1987), who investigated the role of adult caregivers providing support for ageing parents. The friend indicates that he must prevent his own health breaking down, so that he can continue to care. His response at Time D identifies his need for more help with care, particularly in encouraging Mrs G.N. to attend CREST.

Husband carers

Husband caring for Mrs N.S., whose responses became more positive over time

Time A

> "I wish she didn't have to go, that she was well enough to stay at home but having said that it gives me a great break. CREST is good because when she goes I am free for a while and I get to sleep. She asks why do I send her and I tell her I need sleep, my head gets 'muzzy', she understands what I tell her."

The reasons he gave for feeling like this were:

> "It's her sleep problem and she keeps calling for the commode to pass urine. I put her on it and back to bed then ten minutes later she wants up again and this goes on and on. She says she didn't use it, it is very exhausting. You have to have a lot of patience to keep telling her she has just been out of bed. I don't like to see her going out at night, since February there has been a change in her, she wasn't sleeping, then she had a stroke. I have to support her up and down stairs to bed."

Time D

> "I get my rest, I get a night's sleep when my wife is here she wants to be taken to the toilet often, every 15 minutes, she doesn't want to wet the bed and cannot use the pads. I feel guilty about sending her out to sleep somewhere else but I could not keep going without this help at night."

The reasons he gave for feeling like this were:

> "It is a wonderful facility and I hope it keeps going on. You see my wife is very strong minded and insists on me waiting on her, it is a bit much at times but she can't help it all the time."

Mr N.S. cared for his wife at home for nearly three years while she attended CREST and day care. She eventually died at home. Interview data collected at Times A and D indicated that he valued CREST both in terms of the care his wife received and the break from caring it gave him. At Time A he wished that she did not have to go to CREST, but at Time D he had reached an acceptance of his need for her to use the service and did not re-report this feeling. Mr N.S. was interviewed one year after his wife's first attendance, his response at that time indicated that his wife's sleeping pattern had improved, which had made his role much easier.

Time E

> "I would really like to have her at home if I could. Although she is sleeping much better now things are very different now to a year ago."

The reasons he gave for feeling like this were:

> "CREST has been a wonderful big help to me when her sleeping was very difficult, I was at the end. CREST was wonderful it was a real lifesaver, she is much better now at night, quieter and sleeps for very long periods."

Seven of the ten carers continued to report positive changes in their lifestyle, which they attributed to their relative/friend's attendance at CREST. Two carers said that CREST no longer gave them the extent of support they required for their relative/friend. In one instance this was because the patient had recently had a stroke and was in hospital. The wife carer of this patient said that she did not think that CREST would help her enough if her husband was discharged from hospital. The other carer, a daughter looking after her mother, said that she had appreciated the service but that she wished it to start much earlier so that she could go and do the things she enjoyed: for example, to a Tupperware party.

They all reported that they were better able to sleep, five said they were coping better and four felt more relaxed. In addition, six said they no longer had to bath their relatives as this was done at CREST and three reported that their relatives had become more mobile since attending CREST. It was unclear how this greater mobility had changed carers' lives. Three carers, two wives and one husband reported that they believed CREST had contributed to them keeping their relative at home.

9.3.6 Carer feelings and request for patients admission to long-term care

Asking carers how they felt about their relative/friend attending CREST indicated that carers' feelings might be associated with admission of dementia sufferers to long term care. Those carers who remained emotionally attached to the people for whom they provided care generally valued CREST because it enabled them to go on supporting their relatives at home. Those carers whose feelings regarding their relatives' attendance at CREST were predominantly related to personal relief, associated with a reduction in the burden of caring, also valued CREST but in time often made requests for long term care for dementia sufferers. Emotional attachment between carer and the person receiving care appeared to be a key criterion associated with keeping the CREST patients at home, as has been illustrated in other studies (Levin et al, 1989; Smith and Cantley, 1985).

9.4 Other support services used by CREST patients and their carers

9.4.1 Question 3, Time A

The third question asked at carer interviews was:

3a) What services were you receiving prior to your relative/friend's attendance at the night hospital:

CPN
Social Worker
District Nurse
Meals on Wheels
Home help
Other

3b) Has this changed?

The purpose of these questions was to identify changes in the use of community nursing and social services associated with patients' attendance at CREST. Carers were encouraged to identify the services that they used in addition to those listed in question 3a.

They reported being in receipt of the following services prior to the patient's attendance at CREST:

Community psychiatric nurse		1
Social Worker		4
District Nurse		19
Meals on Wheels		1
Home help		5
Day Hospital	Psychogeriatric	2
	Geriatric Day Unit	1
Day Centre		6
Crossroads		2
Incontinence Service		10

Only one carer reported having no other outside help. In fact, 14 patients regularly attended both CREST and day care (Section 8.4.2), not only the nine patients identified by carers, indicating some under-reporting by carers of the use of day hospitals.

The carer who reported having had a community psychiatric nursing service said the nurse had visited once and encouraged her to re-contact the nurse if necessary. Social workers' visits were reported as "sporadic", but carers knew how to contact social workers. The other services were received on a regular basis.

Twenty carers said there had been no alteration to the services they received, their relative/friend was attending CREST in addition to rather than instead of another service.

District nurses were the most commonly used service by patients and their carers with up to three visits a day occurring in some households. Five carers said that there was an alteration to the district nursing service they received as a result of their relative/friend using CREST. In total the district nursing service was reduced by 18 visits a week to the five patients involved (Figure 9.3).

Two carers believed that they were reducing their use of the incontinence service because of their relative's attendance at CREST; one of these carers had also reported a reduction in district nursing visiting.

1. District nurse no longer visits one patient to bathe him as he has a bath at CREST. Previously being visited once a week for this purpose.

2. One carer had help every night from two district nurses to put her relative to bed - this had been reduced from seven to three visits a week as he attended CREST four nights.

3. One carer and patient had been having three visits a day from the district nurse seven days a week. This had been reduced during the week because of CREST, a reduction in total of eight visits a week.

4. One patient attending CREST for two nights a week resulting in a reduction of two district nursing visits a week, similarly another attending three nights reducing visits by three a week.

Figure 9.3 Reduction in use of district nursing service

9.4.2 Question 3, Times B and C

At Time B (six weeks after patients' first attendance at CREST), when 18 carers were interviewed, they reported having similar services to those reported at Time A. Reductions in the use of district nursing services had continued for patients still attending CREST. One carer reported that her husband had just been admitted to long term care and it was doubtful that he would return home, thus reducing her need for any supportive community nursing services, including CREST.

At Time C (three months after patients' first attendance at CREST), 12 of the 16 carers interviewed reported that their relatives were in receipt of services similar to those prior to using CREST. The other four carers each reported one of the following changes:

a) A community psychiatric nurse was visiting regularly once a month; previously this service had not been used.

b) District nurses were attending every night to assist a patient to bed except when they were attending CREST; previously the carer had managed this alone.

c) Another carer reported that the district nurse was still not attending (as in Time A) because the patient was being bathed at CREST.

d) Another carer reported that the CREST patient was in respite care temporarily because the carer was going into hospital for an operation.

The reduction in district nurse visits was less evident at Time C than Time A. This appeared to be because three of the patients who had required maximum help from district nurses had been admitted to long term care, and two others had died. Therefore, most patients who attended CREST for as long as three months had not been receiving two or three visits a day from district nurses before coming to CREST.

9.4.3 Question 3, Time D

At Time D (six months after patients' first attendance at CREST), when 10 carers were interviewed, there had been changes in services used by the patients since the Time C interviews:

a) One patient had changed from attending a day centre to the elderly mental health day hospital following a visit from the community psychiatric nurse.

b) One patient had extra assistance from a district nurse in treating a pressure sore.

In addition, one patient had been an in-patient for seven weeks between this and the previous interview.

Of the 10 patients still attending CREST after six months whose carers were interviewed at Time D, eight were receiving district nurse support, five spent two days a week at the geriatric day hospital, and another attended the psychogeriatric day hospital on a regular basis up to a maximum of four days a week. These findings show that most carers required more assistance with caring for their relatives than could be offered by the CREST service.

9.5 Effect of CREST on carers: summary and conclusions

Six months after patients first attended CREST there was a positive correlation (r_s +0.81, $p < 0.01$) between carers' and nurses' ratings of patients using the Crichton Visual Analogue Scale, which had increased from r_s +0.46, $p < 0.05$ at Time A. This can be interpreted as a positive finding, in that carers' and nurses' ratings of patients began to converge as a result of working together in delivering care.

Carers did not report any change in anxiety about or ability to cope with dementia sufferers who attended CREST over periods of up to six months (Section 9.2.2, Tables 9.3a and 9.3b). Carers' levels of anxiety about and ability to cope with CREST patients at Time A (within one week of admission) were not associated with patient outcome (Section 9.2.2). It is concluded that despite most carers experiencing comparable levels of anxiety about and ability to cope with caring for CREST patients, some were able to continue support at home, while others requested long term residential care for dementia sufferers. The interview information indicates that carers' ability to continue in their caring role was more likely to be associated with the relief they obtained from using CREST and their feelings concerning caring for CREST patients.

Twenty two carers (n=26) expressed positive feelings about their relative or friend attending CREST at Time A. These feelings were attributed to the respite from caring they experienced. Eight carers referred to the quality of care at CREST and inferred that this was important to their acceptance of CREST. Carers used words including "they are kind", "it's clean there", "they care for him/her" to indicate the quality factors they recognised at CREST. At Time D, six months after patients had first attended CREST, carers reported more mixed feelings about their relative/friend's attendance at CREST. Two carers compared CREST to respite care and indicated that CREST was preferable because the quality of physical nursing care was better. Carers continued to report positive perceptions of CREST because their relative/friend returned home washed and dressed in the mornings, thus reducing their need to undertake these tasks. Those carers who remained emotionally attached to and were able to identify the advantages of caring for their relatives appeared to be better able to cope with their role than could carers who had little emotional attachment and considered their role from an instrumental perspective. Although not conclusive there appears to be a relationship between patients' admission to long term care and carers who reported their role in terms of burden.

Twenty six carers (n=27) reported positive changes in their lifestyle within one week as a result of their relative/friend's attendance at CREST. The majority reported feeling better in themselves and being able to have a good night's sleep. Ten carers reported feeling better able to cope and nine were more relaxed. A reduction in conducting physical tasks, including bathing their relative/friend, was reported by six carers who appreciated that CREST staff provided this service to patients. These positive findings were consistently reported by carers at the six and 12 week interviews. Of the 10 carers interviewed at six months, seven continued to report positive changes to their lifestyles as attributed to CREST. Three carers expressed the need for more assistance with caring than CREST could offer. Three carers, two wives and a husband, reported that CREST had contributed to them keeping their relative at home.

CREST patients and their carers used other health and social services in addition to CREST. Those most frequently utilised were the district nursing service, day care and the incontinence service. A reduction in the use of the district nursing service by five patients was attributable to their attendance at CREST. These were patients who had required assistance from district nurses with going to bed and getting up in the morning. This help was not necessary when patients attended CREST, but continued on those days when patients either remained at home or went to day care. The results demonstrated that the majority of carers required more assistance with their role than CREST could offer. CREST was regarded as a valuable service by most carers, particularly for patients who were restless at night. Other carers found sending their relative/friend out at night difficult and chose to use alternative forms of care, including regular respite and the night sitting service.

Patients with dementia at home are difficult to support with community based service provision (Challis and Davies, 1986; Levin et al, 1989; Twigg, 1993). The motivation of carers and their willingness to continue in the caring role is a key influence on whether patients are able to remain at home (Bergmann et al, 1983; Qureshi and Walker, 1989). The results presented here indicate that CREST provided practical relief to most carers of the patients who attended.

Some carers attributed positive changes in their own feelings concerning their ability to cope with caring because of their relative or friends' attendance at CREST. CREST did, therefore, achieve its aim of providing support and relief to the majority of carers of patients. Other carers were less specific about the contribution of CREST to their continuing caring role. For some carers the use of CREST appeared to be the catalyst that prompted them to request long term care for their relative. Smith and Cantley (1985) reported that the psychogeriatric day hospital did little to prevent patients from being admitted to long term care. The results from CREST are more positive. As part of a combination of a package of community services tailored to the needs of each individual carer and the patient for whom they care CREST was successful in supporting carers. Eight carers looked after CREST patients at home until shortly before they died. This finding is indicates that CREST did enable a proportion of carers to keep their relative/friend at home for longer than might otherwise have been feasible.

CHAPTER 10

DISCUSSION, CONCLUSIONS AND FUTURE RESEARCH

10.1 Introduction

The advantages and disadvantages of CREST to patients and their carers were presented in Chapters 8 and 9. This chapter relates those outcomes to the structure and process of the CREST service described in Chapters 6 and 7. The problems associated with attributing the outcomes for patients and carers to CREST are discussed. Predictive pathways that illustrate the factors which contributed to patient outcome are presented. These lead to the three outcomes which emerged:

- the patient's care at home was maintained with CREST;
- the patient's care at home was maintained without CREST; and
- the patient entered long term residential care.

The methods used to evaluate CREST are reviewed. The review illustrates the strengths and weaknesses associated with the application of a case study, quality assurance framework to the evaluation. Non-participant observation schedules used to record patient and nurse activity at CREST are discussed in the context of the results obtained. The relevance of the nursing framework for practice is examined with particular reference to the review of patients' nursing records and observation of activity at CREST.

In June 1991 a final report containing the results of the CREST evaluation was presented to the project's commissioners. This report included a list of recommendations concerning future provision of night respite services. The extent to which the report influenced decisions about the future structure of services in the Mental Health Unit is explored in relation to contemporary health and social policy.

Finally, reflections on the research are presented, including the author's learning and development during the evaluation together with limitations of the study and ideas for future research.

10.2 Evaluation of CREST

CREST was evaluated against its aims using a quality assurance case study approach (Chapter 6, Section 6.2) (Department of Health, 1993b; Suchman, 1967; Walker, 1980; Weiss, 1986). Two of those aims were to provide a service which supported elderly mentally confused people and their families at night and relieved relatives who were caring for CREST patients at home. In addition, the service was intended to provide individualised programmes of care for each patient, which facilitated independence and dignity, and to support informal carers by working in partnership with them to deliver high quality care to patients (Chapter 6, Section 6.2).

The evaluation of CREST focused on identifying whether the service was appropriate for its patients and whether the service was acceptable and effective. Effectiveness and acceptability were measured from both patients' and carers' perspectives. There is an increasing awareness of the need to measure the impact of nursing interventions on patient outcome although little research in this field has been conducted (Barriball and Mackenzie, 1993; Bond, 1991; Bond et al, 1989; Bond and Thomas, 1992; Goldstone and Doggett, 1990; Hill and Leiper, 1992; Luker, 1981; Marsland and Gissane, 1992; Neufeld and Strang, 1992; Pearson, 1988). A major reason for the paucity of research on evaluation of outcomes of nursing care is the difficulty involved in attributing patient outcomes to specific nursing interventions (Barriball and Mackenzie, 1993; Bloch, 1975; Bond et al, 1989; Davidson, 1977; Gibbs et al, 1991; Hill and Leiper, 1992; St Ledger et al, 1992; Smith and Cantley, 1985). The work presented here illustrates this difficulty. Although the patient and carer outcomes reported in Chapters 8 and 9 were related to CREST, the relationship cannot be confirmed as causal and most of patients and carers used other health and social services in conjunction with CREST (Figure 10.1). Therefore, it is difficult to isolate the contribution of CREST from the other inputs received by carers and patients. The main reason for rejecting an experimental research design was that the managers of the service saw this as ethically unjustifiable on the grounds that CREST should be available to all prospective patients.

The evaluation of CREST was designed to identify the additional services used by patients and their carers so that the outcomes could be considered in the context of the mixed packages of care that each "caregiving unit" (patient and carer) received. The design also incorporated CREST's structure and processes. This approach has been recommended so that outcomes can be related to possible contributory factors (Bloch, 1975; Clarke, 1984;

Donabedian, 1969; Luker, 1981; Marsland and Gissane, 1992; St Ledger et al, 1992). The advantages and disadvantages of CREST are discussed with particular reference to those factors which influenced patient and carer outcomes.

10.3 The CREST service (structure and process) and outcome

The CREST philosophy was that the service should be developed around the individual needs of each patient and family (Chapter 6, Figure 6.1). Two aims of CREST were to provide individualised programmes of care for patients which enhanced their independence and dignity and to provide a service which supported informal carers by working in partnership with them to deliver high quality care to patients.

10.3.1 Operational policy and nursing standards

The structural standards for CREST (Chapter 6, Section 6.2) were reviewed during the first year of operation and altered with the aim of meeting best the requirements of patients and their carers. The quality assurance system used by nurses and managers at CREST to reflect on practice resulted in changes to operational policy. Ideas for change were canvassed from patients' carers, patients and staff working in CREST. The CREST management committee met once a month to receive recommendations for change based on the opinions of users and delivers of the service. This 'bottom-up' approach to quality review was successful, because there was a system for communication between service deliverer and managers which was facilitated by managerial support (Audit Commission, 1992; Fain, 1985; Lancaster, 1985).

The main changes in operational policy involved extending the hours of operation and enabling patients to attend day care in conjunction with CREST (Chapter 7). These changes meant that carers could receive regular breaks from caring for 24 or 36 hours once or twice a week. Carers particularly appreciated receiving a break of this length (Chapter 9, Section 9.4). The need for regular reliable breaks at least once a week for carers of people with Alzheimer's disease being supported at home has been identified in other studies (Alzheimer's Disease Society, 1991; Twigg et al, 1990; Levin et al, 1989).

In order to provide 24 hour breaks for carers, patients had to attend both day care and CREST. The mental health day hospital for elderly people was three miles from CREST, which made it difficult to transport patients between the two services. Although some patients appeared to enjoy travelling, lengthy journeys in rush hour traffic were not consistent with the service aim of providing individualised care facilitating independence and dignity (Chapter 6, Section 6.1.1). Carers also disliked the fact that their relatives had to be taken between two sites to ensure a longer break from caring.

It has been argued that carers of elderly confused people should be able to select the services which they believe would be most useful in enabling them to care for the relative or friend at home (Twigg, 1993). If carer choice is to be taken seriously facilities cannot be run to full capacity: vacancies must exist so that they are available when needed (Twigg, 1993). During the period that CREST was investigated there were always vacancies for new referrals.

10.3.2 Nursing standards and the stress management, activities of living framework for care

Patient care was consistent with the standards for practice concerning individual assessment, management of incontinence, pressure sore prevention, personal hygiene and freedom of movement (Chapter 6, Figure 6.3 and Chapter 7, Section 7.5). All grades of nurse spent the majority of their working time involved in clinical care with a range from 65% to 90%, a higher percentage than was identified in the study examining work of nurses at night in medical and surgical wards (NHS Management Consultancy Services, 1987).

Although the number and grade mix of staff was altered during the period investigated, further revision should be undertaken to maximise cost effectiveness. Nursing staff were under employed between the hours of 11.30 p.m. and 6.00 a.m. The nursing assistants at CREST became conversant with the way in which qualified nurses expected care to be conducted. This resulted in nursing assistants undertaking patient orientated care activities with minimal supervision from trained nurses during the third period sampled. Nursing assistants are a central component of the nursing staff workforce in areas that provide care for elderly people (Fall and Bond, 1991; Johns, 1992; Pearson, 1988; Pembrey, 1975). It is possible that effective nursing teams for CREST patients could be developed by using only qualified primary nurses and health care assistants. The health care assistants could undertake activities traditionally considered those of both associate and assistant nurses (Robinson et al, 1989; Rowden, 1989).

It was anticipated that the application of the stress management - activities of living framework for care would promote patients' independence and dignity and enable carers and nurses to work in partnership (Chapter 6, Section 6.4, Figure 6.2). The observation of patient and nursing staff activity at CREST demonstrated that patients were treated as individuals and that patients' independence was encouraged. One aim of the nursing framework was to ensure that patients were treated with dignity. It is difficult to isolate criteria which assess "dignity". Gilloran et al (1993) suggest that patient choice, giving information, independence, privacy, nursing patient interaction and supervision are all indicators of dignity in health care for elderly people. The non-participant observation schedules used to categorise the patient activity observed at CREST identified that patient and nurse interaction occurred and that nurses supervised patients and assisted them with activities of living when help was required (Chapter 7, Section 7.4 and Chapter 8, Section 8.4). The schedules were not designed to capture the extent of choice and information given to patients by nursing staff as recommended by Gilloran et al (1993). The information collected is sufficient to indicate that patients were treated with dignity and offered privacy when at CREST.

Some patients displayed behavioural problems including shouting, volatile emotions and restlessness when at CREST. Both Bergman

(1983 and 1986) and Kitson (1986 and 1987) regard an emotional commitment by nurses to patients as an indicator of high quality care. Nursing staff responded to patients' behavioural problems by attempting to reassure or comfort them using both verbal interaction and/or physical comforting actions, such as stroking a patient's arm, holding a patient's hand or embracing a patient, indicating an emotional commitment in caring. In some instances a patient's distress, expressed by shouting or agitation, was resolved by practical nursing interventions including taking a patient to the toilet or turning patients in bed to make them more comfortable.

The review of nursing care plans revealed that individual assessments of patients' needs were conducted by primary nurses in conjunction with carers. The majority of patients' written nursing care plans reflected the framework for nursing practice. The activities of living focus was appropriate because most of the patients required assistance with at least one activity (Chapter 8, Section 8.4). The information collection from observation of patient activity and review of nursing notes indicates that the activity of living stress-adaptation model of framework for care actually influenced individual patients' care in action.

Advantages of the stress management framework for care were identified by carers, who reported working closely with their relative's primary nurse (Chapter 9, Section 9.3). Carers of CREST patients reported that primary nurses gave them information about their relative's disease and the availability of other health and social services which might assist them in their caring role.

Information giving was a central component for the framework of practice and the results indicate that nurses operationalised this element of the framework. Sharing information between professionals and carers has been identified as being particularly valuable for families looking after people with Alzheimer's disease at home (Alzheimer's Disease Society, 1991). The significant positive correlation between nurses' and carers' ratings of patients (on the Crichton Visual Analogue Scale) increased over periods of patients' attendance at CREST (Chapter 9, Section 9.2 Table 9.2). That nurses' and carers' perceptions of patients gradually converged is an indication that they worked closely together and exchanged information about patients. It facilitated primary nurses and carers in working together to meet best the needs of patients.

In conclusion, the framework for care at CREST met the criterion of applicability as defined by Guba and Lincoln (1981) (Chapter 6, Figure 6.1). The framework was appropriate for the patient population because it facilitated primary nurses and carers in working together to meet best the needs of patients. The framework was published in 1989 and has since been adapted for use by a community mental health team in Scotland (Wicks, 1990). More recently the development of carer led assessments of elderly confused people living at home, using the framework as a central focus for planning community care for this client group, has been reported (Keady and Nolan, 1994). The adaptation and application of the framework by others leads to the conclusion that nurses involved with caring for elderly people have judged it to be credible and relevant to practice (Guba and Lincoln, 1981).

10.4 Patient and carer outcomes following periods at CREST

CREST was developed to support elderly mentally confused people and their families at night (Chapter 6, Section 6.2). The service achieved this aim for some carers and patients.

10.4.1 Patient activity and outcome

Whether CREST was an appropriate service for its patients can be judged from two perspectives; those of patient activity at CREST and patient outcome. The results of the non-participant observation of patients' activity at CREST indicated that many patients conducted their own activities of living safely, with minimal assistance from nursing staff. Patients spent periods of time alone in self-contained behaviour. Patients talked with each other and nursing staff when at CREST suggesting that they did not suffer the sensory deprivation associated with some long term institutional care provision (Robb, 1967). Although sleep patterns varied, most patients slept for long periods when at CREST, normally between 11.30 p.m. and 7.00 a.m. Some patients woke several times during the night and required assistance with visits to the toilet and reassurance or comfort prior to returning to sleep. Nursing staff were able to respond quickly to patients' needs and many rapidly returned to sleep following relevant nursing interventions.

CREST's operational policy and nursing framework for care provided a structured care setting more akin to that of the NHS nursing homes (Bond et al, 1989) than to the unstructured provision at Oundle night hospital (Gibbins, 1983). The success of patient care at CREST was related to nursing staff clearly understanding and articulating the responsibilities expected of them (Fain, 1985; Lancaster, 1985).

The Crichton Visual Analogue Scale was used to measure patient outcome. The main reasons for selecting this scale were that it was designed to measure behavioural criteria which are associated with dementia, and was formulated for use by both carers and nurses (Morrison, 1983). No significant difference between patients' ratings conducted by primary nurses and carers was identified between initial ratings taken within one week of admission (Time A) when compared with measures taken at six weeks (Time B), 12 weeks (Time C) and six months (Time D) after initial attendance. Alzheimer's disease, multi-infarct dementia and other illnesses which are categorised as dementia are all progressive disorders (Lishman, 1987), therefore the results from the Crichton Scale indicate a positive outcome for people who attended CREST. This outcome cannot be attributed entirely to CREST, as some patients were also in receipt of other health and social services. When the results of the Crichton Scale are considered in relation to patient and nurse activity at CREST it is concluded that the process of care at CREST was effective in terms of promoting patients' independence and minimising preventable deterioration of individual patients.

CREST had some positive advantages when compared to day hospital services. When heavily, physically dependent patients attend day hospitals their carers have to assist them both to get up in the morning and to go to bed in the evening. In some instances carers need help from the district nursing service in order to do these tasks. Patients who attended CREST were assisted by nurses when both going to bed and getting up in the morning. CREST patients were able to have a bath or shower, with assistance as appropriate, either before going to bed and/or in the morning. When attending day hospitals patients have to get undressed during the day to have baths if this task cannot be conducted at home. Therefore, for patients who attended CREST more normal patterns of personal hygiene, preparation for sleep and morning routines were followed than have been achieved at day hospitals.

One advantage of CREST was that eight patients were supported at home until shortly before they died. In common with carers identified in other studies the carers of these eight patients wanted to support their relatives at home for as long as they could manage (Alzheimer's Disease Society, 1991; Levin et al, 1989; Qureshi and Walker, 1989; Twigg et al, 1990). These carers are usually spouses. Six of the eight patients who died while registered at CREST were in this category. The interview results clearly demonstrate that the carers who did keep their relatives at home until shortly before death valued the contribution of CREST.

Half of the CREST patients were admitted to long term care, often because carers decided that they were unable to continue to support their relative at home. This finding was consistent with other studies, including the Kent Community Care Scheme (Challis and Davies, 1986) and Levin et al's (1989) study of carers in London. It is unlikely that extending CREST provision from four to seven nights a week would have resulted in more patients remaining at home rather than entering residential care. When the burden of caring outweighs the benefits, carers review their position (Barusch, 1988; Bergmann et al, 1984; Biegel et al, 1991; Finch and Groves, 1983; Finley et al, 1988; Levin et al, 1989; Sainsbury and Grad de Alarcon, 1970; Sanford, 1970; Qureshi and Walker, 1989). Individual cases reported in Chapter 9 demonstrate that, for some carers, their relative's attendance at CREST enabled them to make the decision to give up the caring role; using CREST was, in fact, the first step in deciding to give up caring.

Smith and Cantley (1985) found that the day hospital did little to prevent people with dementia being admitted to residential care. Likewise, the CREST evaluation suggests that the service did little to prevent patients being admitted to residential care once carers decided that they wanted to give up caring. No association between patients' dependence as measured on the Crichton Scale at Time A and outcome was identified (Chapter 8, Section 8.4). Therefore, CREST was only an appropriate service for those patients whose carers wished to go on caring but required respite and rest on a regular basis, so that they had sufficient energy to continue supporting their relative or friend.

10.4.2 Carers' feelings and outcomes

Carers of CREST patients reported positive changes in their day to day lives because of their relative or friend's attendance at CREST (Chapter 9, Sections 9.3 and 9.4). These advantages ranged from increased sleep and improved mood to a reduction in physical burden as a result of patients being bathed and dressed at CREST. CREST did not result in carers feeling less anxious about their relatives or their ability to cope with the person for whom they cared.

Previous studies have demonstrated that carers' anxiety about and perceived ability to cope correlate with the extent of the disability of the person for whom they care (Bergmann et al, 1984; Finley et al, 1988; Gilhooly, 1986; Morrison, 1983; Nolan et al, 1990; Watkins, 1987a). Patients did not improve in their behaviour as measured on the Crichton Scale while attending CREST. This may explain why carers did not identify any change in their feelings concerning their relatives when rating these two items.

It is clear that CREST provided relief for carers at night which resulted in positive benefits to their day to day lives. CREST was an appropriate service for those carers who wanted to continue to support their relative or friend at home. For other carers residential care was perceived as a more desirable alternative than continuing to care for their relative or friend at home. In such circumstances CREST was not an appropriate long term service for patients.

Carers identified positive attributes of CREST in terms of quality, including its cleanliness and the friendliness of staff. They also highlighted disadvantages of the service, which included late collection of patients from home and issues concerned with sending elderly people out at night in the dark. These results partially counter the argument that the ability of the consumer to appreciate the quality of health care remains low and therefore that the validity of consumer surveys is questionable (Berliner, 1990; St Ledger et al, 1992). Hudson (1990) asserts that the results of consumer surveys may be affected by participants' perceptions of the behaviour of one particular practitioner rather than the service as a whole. It was the intention that the primary nurses working with individual patients and their carers should influence carers' opinions concerning CREST. Therefore, the fact that consumers may be influenced by one practitioner, i.e. their primary nurse, was an advantage in this study, where one aim of the evaluation was to establish carers' perceptions of CREST from their viewpoint as individuals involved in receiving the service.

10.4.3 CREST as part of a comprehensive service

CREST was developed as part of a comprehensive mental health service for dementia sufferers and their carers (Chapter 6, Section 6.2). During the 18-month period in which CREST was evaluated (1989-1990) the Health Authority provided long term in-patient care for elderly people who suffered from dementia and nursing home places were funded from the social security budget for those who needed and requested that form of care. Five patients who attended CREST were admitted for long term hospital care, eight to nursing homes and one to a social service residential facility. It is clear that carers of patients who attended CREST were able to choose between using community based services and keeping their relatives in their own homes or arranging for their relative to be admitted to long term residential care.

Whether carers will continue to be able to choose is now affected by implementation of the Community Care Act (Department of Health, 1990) which came into force in April 1993. Social service and health departments with limited financial resources can purchase flexible services, like CREST, to support carers and restrict the number of publicly funded residential places available to people with dementia. If this were to occur, the advantage of CREST in enabling some patients to remain at home for longer periods than might otherwise have been possible would remain. Conversely, the option taken by many carers in the CREST evaluation to give up their role and arrange for their relative or friend to be admitted to residential care may be denied to carers in the future. The development of flexible community services like CREST may reduce rather than increase the range of publicly financed options open to elderly confused people and their carers.

CREST was regarded as an acceptable service for patients who continued to attend and was effective in terms of both patient and carer outcome for those patients. The service was not acceptable to a proportion of carers and patients. In these instances patients stopped attending CREST mainly because they had refused, and carers found alternative forms of care. The results of the evaluation demonstrate that most patients who attended CREST were admitted for short periods to either in-patient care for treatment or respite care while registered at CREST. CREST was not, therefore, so comprehensive a service that it could totally support its patients and carers in isolation from residential health care provision. In addition, some patients required community based services including district nursing, social work and incontinence services, as well as CREST, to enable care to be conducted at home (Chapter 9, Section 9.4). In conclusion, the first two aims of CREST, to support elderly mentally confused people and their families and to give carers a break at night were achieved (Chapter 6, Section 6.2).

10.5 Caregiver motivation, patients' problems and patient outcome

10.5.1 Caregiver motivation

There was no difference between carers' levels of anxiety about and ability to cope with CREST patients at Time A (within one week of initial attendance) and patient outcome (Chapter 9, Section 9.2.2). Carers who continued to support patients at home for six months did not report a change in anxiety or coping when compared to Time A. These findings suggest that carers' motivation rather than anxiety and coping was a key factor in contributing to patient outcome.

The information collected from carers' interviews indicates that for some carers CREST gave them sufficient support, in combination with other services, to continue caregiving. It had been intended to analyse information to identify whether there was an association between carer relationships and patient outcome; this was not possible because of sample sizes (Chapter 8, Section 8.5.2, Table 8.14). However, information collected at interview indicated that there was a relationship between the emotional commitment of carers to CREST patients and patient outcome.

Carers who had long standing emotional commitments to the CREST patient for whom they cared were motivated to continue caring. Spouse carers most frequently reported emotional commitments. Biegel et al's (1991) theory that attachment, kinship and prior interaction are relevant to caregiving situations was supported by CREST carers' responses, some of whom reported a 40-50 year relationship with the person for whom they cared.

A proportion of CREST carers indicated that they had altruistic reasons for continuing in the caregiving role which were associated with wishing to give CREST patients the best possible care in the circumstances, a finding widely reported in other studies (Bergmann et al, 1983; Biegel et al, 1991; Dawson, 1987; EOC, 1982a,b; Finch and Groves, 1983; Finley et al, 1988; Levin et al, 1989). Some carers reported egotistical reasons for continuing to care, including the fear of loneliness and avoiding guilt. These motivators have been identified in other studies examined in Chapter 3 (Brody, 1985; Greengross, 1982; Levin et al, 1989). The fear of loneliness was more frequently reported by spouse and spinster daughter carers than by others, presumably because they would be living alone in the event of CREST patients being admitted to residential care.

The three carers of patients who attended CREST for more than a year, a wife, husband and male friend of a female patient, all indicated continued emotional commitment to those they supported. Six of the eight carers of patients who died while registered at CREST also indicated similar feelings.

Conversely, when carers reported their caregiving role in instrumental terms focusing on the burden and work associated with caregiving, they appeared to be less willing to continue caring. For example, two carer daughters eventually sought residential care for their mothers. Both the daughters had other family commitments and decided to consider their own spouses' and childrens' interests in addition to their mother's, which had influenced their decisions. However, these carers also talked about the heavy workload burden of caring for their mothers and indicated that this gave them very little emotional satisfaction.

Some patients were discharged home from CREST. In these instances carers' responses at interview indicated that they wished to care for their relative at home for as long as possible with appropriate support. At least four patients were discharged because they or their carer did not like CREST. In other instances the patient's or carer's health improved enabling the carer to resume caregiving without the assistance of CREST. These examples illustrate that a high proportion of CREST carers were willing to undertake the responsibility for the majority of their relative's care at home, as has been demonstrated in other studies reported in Chapter 3.

It is concluded that carers' motivation influenced patient outcome. The motivation to continue caring was stronger in spouse and spinster carers than in daughters and sons who were supporting a parent but also had families of their own. The conflicting demands on carers who also had their own families often resulted in requests for residential care for CREST patients.

10.5.2 Carers' stress, family structure and patient problems

The CREST study did not assess carers' stress levels or their general health. Other studies have found a direct association between caregivers' psychological health problems as measured on the General Health Questionnaire and the severity of problems associated with dementia suffered by the person for whom they cared (Eagles et al, 1987; Levin et al, 1989). In addition, family stress has been acknowledged to be a factor in caring for elderly people (Adams, 1989). The information collected at interview indicated that carers whose only demand was the dementia sufferer were often more able to continue caring than when other family demands were made. CREST enabled some carers to continue caring by reducing their burden of caring by allowing them time to themselves, time for socialising and regular sleep at night. The advantages of regular sleep cannot be over emphasised; previous studies have found that chronic lack of sleep leads to carers feeling totally unable to cope and is associated with patient admission to long term care (Gilleard, 1984; Green et al, 1982; Hirschfield, 1978; Levin et al, 1989; Sainsbury and Grad de Alarçon, 1970; Sanford, 1975). Indeed, when carers feel tied down and suffer from lack of personal time they develop feelings of resentment and hopelessness concerning caring at home (Hirschfield, 1983; Levin, 1989).

Carers reported finding certain problems which CREST patients presented as more stressful than others. In particular, carers were concerned about patients who were difficult, wandered, needed assistance at night due to frequent waking and were incontinent. Also carers found it particularly distressing when the person for whom they cared no longer recognised them. These findings are consistent with other studies of caregivers of people who have dementia (Bergmann et al, 1978; Gilleard et al, 1984; Green et al, 1982; Levin et al, 1979; Sanford, 1975). The problems that carers found particularly difficult appeared to decrease their motivation to continue to support relatives at home.

CREST was helpful to carers particularly when nurses took on some personal care tasks which they found difficult to perform, including washing patients and more traditional nursing tasks such as dressings and catheter care. Previous studies have indicated that if statutory services assist carers with the tasks they find most difficult carers are more likely able to continue supporting people with dementia at home (Levin et al, 1989; Twigg, 1992 and 1993; Twigg and Atkin, 1992). However, despite the assistance from CREST, some carers stated that they were no longer able to cope with caring particularly when their relatives were restless and incontinent at night. It is suggested that, although there was no statistically significant association between patient behaviour (as rated by both nurses and carers on the Crichton Visual Analogue Scale) and patient outcome, there was a link between CREST patients' behaviour, carers' motivation, family structure and patient outcome.

10.5.3 Factors which affected patient outcome

It is concluded that patient outcome was affected by patient behaviour and caregivers' commitment and motivation to patients. In addition, carers whose primary concern was a CREST patient appeared to be better able to continue in their caring role than those who had other family commitments. CREST provided appropriate respite for some carers in association with other services, which enabled carers to continue to cope at home. In these instances CREST appeared to act as a mediator, reducing the potential for excessive carer burden (Lazarus, 1976). For other carers CREST did not provide sufficient respite and support for them to continue to support dementia sufferers at home. Figure 10.2 presents pathways which indicate the relationship between factors affecting CREST patient outcome.

The key factors which may enable prediction of patient outcome appear to involve the extent of carers' emotional commitment to patients, family structure and patient's willingness or otherwise to use CREST. Three predictive pathways emerged. Pathway A presents factors which were related to CREST patients' entering long term care (outcome X in Figure 10.2). The second pathway, B, presents factors related to CREST patients' remaining registered for periods of six months or more or until shortly before they died (outcome Z in Figure 10.2). The third pathway, C, shows that some patients left CREST and their care was maintained at home without the use of the service (outcome Y in Figure 10.2). In order to gain a theoretical understanding those factors and processes which were predominantly related to particular patient outcomes (X, Y or Z) are discussed.

In pathway A carers requested that their relative or friend use CREST because they no longer felt able to cope, indeed, in some instances carers were ill because of their caring role. At interview this group of carers reported their caring role in terms of 'burden and tasks'; their motivation to care appeared to be decreasing. These findings were often associated with demands being made on carers from other family members particularly when carers were children of the elderly parent they supported at home. For example, the daughter caring for her mother, Mrs V.H., reported the need to support her husband, a prison governor, rather than to continue to care for her mother at home. In this and other cases

CREST was unable to reduce the burden of caring to an acceptable level so that carers could continue to care at home. Carers, therefore, selected residential care for their relative or friend resulting in the individual's discharge from CREST and entry to long term care. Clearly, when the costs of caring outweighed the benefits to carers, care at home was terminated, a finding reported in other studies (Bergmann et al, 1983; Ineichen, 1989; Nolan, 1991; Smith and Cantley, 1985; Watkins, 1987a).

The problem of women "in the middle" trying to care for elderly parents and children have been well recognised by the Equal Opportunities Commission (1982), Brody (1987) and Finch and Groves (1983). The interview data collected in the CREST study suggests that those carers who had very young children frequently found it impossible to continue to care for an elderly parent with severe dementia. Conversely, daughter or son caregivers who either had grown-up children or no other family demands appeared to be more able to cope at home with supportive services including CREST.

For some carers it appeared that the use of CREST was closely related to anticipating the need for long term care as described by Bowers (1987). Bowers argues that carers try to protect their relatives by anticipating the need for future care and preventing them coming to harm either psychologically or physically by providing suitable protective care. In other words, using CREST resulted in a proportion of carers deciding that they were no longer able to provide appropriate care without more help than CREST could offer. An alternative interpretation is that carers may have chosen to give up caring because for the first time they experienced real relief and were able to perceive how their lives could change if they gave up the role. This has been reported by Smith and Cantley (1985) in day hospitals where they suggest that even the provision of five day care did not prevent some patients being admitted to residential care. It has been well recognised that carers cannot always cope with people with severe dementia in the community either because of their own ill health or because of the heavy demands made by patients (Bergmann et al, 1983). This finding was also identified in the CREST study where some patients became too much for carers either through carers' own ill health or the increasing incapacity of the patients themselves. In these instances carers' decisions to choose residential care were planned and they took considerable trouble to ensure that patients entered appropriate long term facilities.

In pathway B carers were able to continue to cope with assistance from CREST which appeared to be related to the extent of their emotional commitment to patients. The length of the relationship between carer and the person cared for, particularly within a marriage, some of which had lasted for over forty years, was a major motivator for carers trying to keep people at home. This finding has been reported extensively in other studies outlined in Chapter 3. In one study of 89 spouse caregivers a general preference for managing situations on their own at home was identified (Barusch, 1988). In Levin et al's (1989) study the majority of spouse caregivers also indicated a preference for keeping their husbands or wives at home whenever possible. In addition to committed spouse caregivers some daughters and sons managed to continue to care for a parent at home with the support of CREST. The results suggests that when other family members assisted carers in supporting people with dementia at home rather than making additional demands on carers, caring was maintained with the support of CREST. Similarly, carers who were only expected to look after the person with dementia appeared to be more able to cope than those carers who had other family demands made upon them. A prime motivator for continuing to care appeared to be carers' desire to continue to cope.

For some carers the provision of CREST did enable them to go on caring and this is illustrated by the fact that eight patients died while registered at CREST. Although the majority were admitted to short term care prior to death, carers actually continued to care for them at home for prolonged periods. A small proportion of patients (three) attended CREST for more than a year and it was clear that the provision of night care assisted those carers in supporting them at home for longer than would have otherwise been possible.

Some patients returned home from CREST and ceased to use night care (outcome Y, sub pathway, C, Figure 10.2). This appeared to be for one of two reasons; either that carers felt more able to cope following a period of their relative's attendance at CREST or that CREST was causing patient or carers disruption or disquiet. The carers who felt more able to cope tended to have been ill themselves and required temporary respite. In other instances CREST led to positive patient behavioural changes including enhanced sleeping patterns, thus reducing the burden of care at night. In one instance the gradual deterioration of a patient had reduced his mobility so that he could no longer wander at night making it possible for his carer to resume night support at home.

Data were not collected concerning the reasons for patients and their carers ceasing to use CREST although information from other studies suggest that respite care can cause increased confusion in patients and it is assumed that this may well have been the reason for some patients ceasing to use CREST. For some carers CREST may not have been an appropriate form of support. The amount of preparation required to enable their relative to go to CREST and waiting for them to arrive home the next morning may have outweighed the benefits from respite received by the carer. Studies of day hospitals have shown that for some carers the effort made to prepare patients to go to the day hospital exceeds the benefits to carers (Smith and Cantley, 1985; Watkins, 1987a).

The pathways (Figure 10.2) illustrate the factors which contributed to patient outcome at CREST and indicate that it may be possible to predict which patients are most likely to have their care maintained at home while attending CREST for prolonged periods. It is concluded that carers emotional commitment to patients, coupled with a lack of demand from other family members, are prime factors in whether or not patients continued to attend CREST. The theoretical model illustrated in Figure 10.2 indicates that if carers are interviewed about their commitment to continue to care and about the other demands made upon them when patients are assessed for admission to CREST it should be possible to identify the patients who are most likely to enter long term care and those who may be supported at home with appropriate community services.

Other studies re-inforce the theory that it is the carers' perception of the stress of caring that is a prime factor in predicting eventual patient outcome (Barusch, 1988; Bergmann et al, 1983; Levin et al, 1989; Nolan, 1991; Watkins, 1987a).

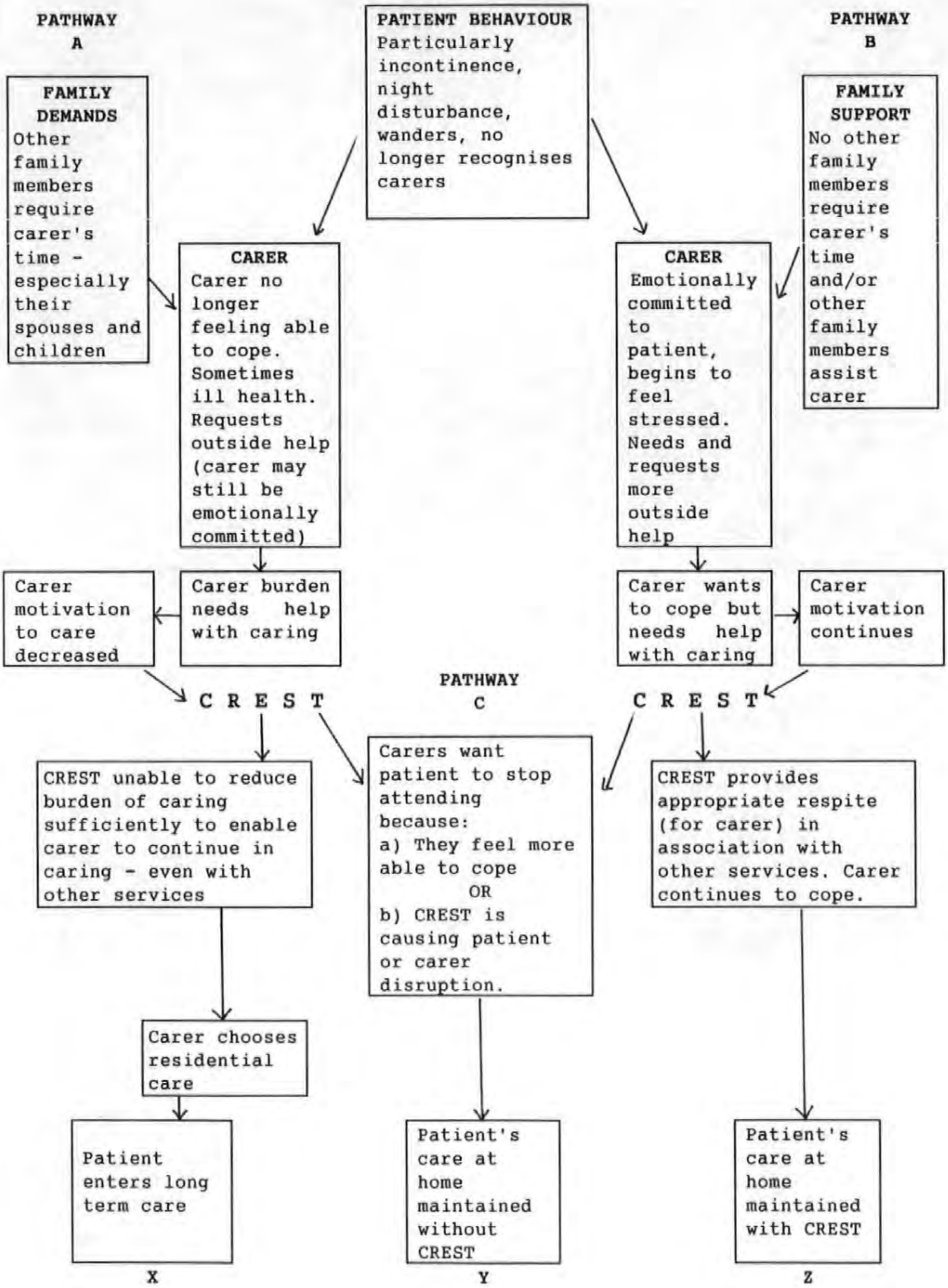


Figure 10.2 Pathways illustrating factors contributing to patient outcome at CREST

10.6 Recommendations to the Health Authority

CREST was evaluated with the intention that the results would be used by managers to inform decisions made concerning long term provision of the service. A report with recommendations based on the results was presented to the unit's chief executive in February 1991. The first recommendation was that "the unit continue to provide a night nursing service outside patients' homes for a maximum of four nights a week". It was considered that any increase in the number of nights' provision could result in patients attending so frequently that long term nursing home care would be a more desirable option. A decision was taken to continue to fund the service until January 1992.

During the summer of 1992 the author presented her report in seminars to members of staff in the mental health unit, social service departments and the health authority, which commissioned services from the mental health unit. The intermediate recommendations made in the report focused on integrating the service within the mental health unit and establishing closer links between health and social service providers supporting individual patients at home (Figure 10.3).

Three recommendations concerning the provision of nursing were made. First it was suggested that the ratio of unqualified to qualified nursing staff be increased because the results of the evaluation indicated that only one qualified nurse was required during the hours of 11.30 p.m. to 6.00 a.m. The second recommendation was that if CREST was integrated with the day hospital one senior

1. Linking the service with day hospital care

   That the service be provided at the same site as the mental health day hospital for elderly people

2. Linking CREST with other community services

   That regular review of patients is undertaken in conjunction with their carers and any other health and social care providers involved in supporting them at home. It is particularly important that liaison exists between district nurses and the night nursing team

3. Attendance

   That most patients attend the service for a consecutive day, night and day once or twice a week, as deemed most appropriate by their carers and nurses. This would reduce travelling time considerably and the need for many patients to travel in the evening. It would also give carers an extended break on a regular basis

4. Linking the service with respite care

   That the night service be closely linked with a traditional respite care facility, so that patients who require a period of short-term, full time care can have this delivered by staff they know

Figure 10.3 Intermediate recommendations for the provision of night services for elderly confused people

nurse (Grade G) could be responsible for assessing all people referred to the service. The third recommendation was that the activities of living stress-adaptation framework of nursing (Chapter 6, Section 6.4, Figure 6.2) should continue to be used when conducting care for the patient group because the results indicated that it contributed to the maintenance of patient independence.

Five longer term interdependent recommendations were made (Figure 10.4) The main mental hospital in the unit is due to close in 1996. At the time of presenting the report decisions about the provision of long term care for patients with dementia were being made. It was anticipated that three purpose built NHS nursing homes of approximately 30 beds each would be constructed. The author suggested to the managers that integration of respite facilities within those homes would facilitate continuity of care for patients and their carers. The model suggested is similar to the Macmillan home nursing service and hospice provision offered to patients with cancer in Britain.

Linking community nursing, day and night care, residential respite care and long term residential care in NHS nursing homes.

1. The intended NHS nursing homes provide tailor made packages of support for patients and their carers. The homes could offer traditional respite care together with day hospital and night nursing services. Patients could attend for periods as deemed appropriate by their carers and centre staff.

2. Each home should offer nursing, physiotherapy and occupational therapy services aimed at assisting patients with their activities of living and promoting independence. Reality orientation and recreational programmes should also be offered in the evening. Chiropody and hairdressing services should be available to patients.

3. Ideally patients could, as they become increasingly dependent, spend more time at the respite centre and less in their own homes (if this becomes necessary) without ever being admitted to traditional long term care.

4. It may be useful to regard the centres as supportive hospices for elderly patients suffering from dementia. Care could also be conducted in the patients' own homes by district nurses and community psychiatric nurses who would be linked to the centres in the same way as Macmillan nurses are to hospices.

Figure 10.4 Long term recommendations for the provision of care in the unit for elderly mentally confused people

10.7 Reflections on the research

10.7.1 Reflections on the evaluation

The quality assurance framework used to evaluate CREST enabled patient and carer outcomes to be related to both the structure and processes of the service. This was an advantage of the evaluation; as Barriball and Mackenzie (1993) and Bloch (1975) suggest, it is important to relate the outcomes of nursing care to the structure and process inputs. Even though the processes of care at CREST were described comprehensively, it was not possible to attribute patient outcome directly to that care. The use of randomised prospective trial for the evaluation may have assisted in isolating the factors at CREST which contributed to patient outcome. The main reason for rejecting this approach was that the managers of the service believed an experimental trial was ethically unjustifiable because CREST should be available to all prospective patients.

The advantages of experimental trials in nursing research "include the testing of hypotheses and the capacity to compare effects of interventions" (Wilson-Barnett, 1991, p.79). Hypothesis testing was incorporated into the evaluative design using patients and carers as their own controls. It was not possible to assign patients randomly to different care groups nor to match patients; this is a common problem for social research (Challis and Darton, 1990). Challis and Davies (1986) matched clients by sex, age and disability when evaluating the Kent Community Care Scheme but were unable to match carers' and clients' household size and other influencing factors. In the CREST evaluation nearly all the patients were supported by a mixed provision of services and one primary carer. This made each "caregiving unit" unique and therefore impossible to match. Therefore, the selection of a case study design which encompassed the requirements of the commissioners was the most appropriate approach to the CREST evaluation (Guba and Lincoln, 1981; Luker, 1981; Walker, 1986; Weiss, 1986).

Although patient choice and dignity were regarded as essential values within the CREST framework and standards for care, patients' opinions about CREST were not sought during the evaluation. An assumption was made by the evaluator that elderly people diagnosed as having dementia would not be able to give coherent opinions regarding the service. However, a small proportion of patients clearly liked attending CREST, while others refused to continue to attend. In future work a method to collect information on the patients' perceptions and experiences would be ideal. The work by Kitwood and Bredin (1992) demonstrates the feasibility of such an approach even with elderly people who have severe dementia. They assert that certain observable patient behaviours are indicative of relative well being in this population. These include the assertion of will or desire, initiation of social contact and humour (Kitwood and Bredin, 1992 p.281). CREST patients demonstrated self will by either consenting or refusing to attend. If another study with elderly people who suffered from dementia were conducted all nine indicators identified by Kitwood and Bredin (1992) would be incorporated within an observation schedule so that individuals' well being could be identified.

Carer interviews were undertaken by two separate interviewers, enabling cross-checking of the information which was collected. The themes which emerged from the two sets of interview information were similar, an indication of credibility as defined by Guba and Lincoln (1981) (Chapter 6, Section, 6.2 Figure 6.1). Similarly, the Crichton Scale data concerning patients' behaviour as rated independently by carers and nurses correlated well (Chapter 8, Section 8.3) suggesting that a degree of credibility was achieved.

The non-participant observation of patient and nurse activity was conducted by the researcher alone. This proved to be the correct decision, as it was frequently necessary to observe patients undertaking intimate activities, such as using the toilet, in confined spaces. The presence of two or more observers would have been obtrusive and unacceptable in terms of preserving patients' privacy. It was, therefore, impossible to cross-check data from the observer sources as suggested by Guba and Lincoln (1981). Another limitation was that it was not possible to judge whether patients were actively engaged when appearing to read or watch television. This type of information could have been collected by asking patients direct questions about what they were doing when they were alone.

The research design did not originally incorporate a cost analysis of CREST per capita. Costs were obtained from the health authority only after changes had been made to the services (Section 10.7.2).

A detailed picture of the service emerged from the information collected. The conclusion is that CREST was an appropriate service for more than half the patients who attended. The evaluation report provided to the health care managers influenced and assisted their decisions concerning future care provision for people with dementia (Section 10.7.2). This finding is indicative of the success of the evaluation.

10.7.2 Future provision in a Mental Health Authority Unit

In order to identify whether the CREST evaluation report had assisted the managers in making decisions about future provision the author returned to a Mental Health Unit in June 1993. The CREST service was still in operation but in an altered form. The service had been attached to an in-patient ward enabling patients to attend for periods of 24 or 36 hours on a regular basis once or twice a week. The ward consisted of 18 beds, 12 for continuing care and six for CREST; each bed was costed at £352 per week. The CREST beds were open seven nights a week resulting in 42 nights' care being available per week. The total cost of the six CREST beds was estimated at £2,112 per week. At the time of the visit 22 patients were using the six CREST beds at an average cost of £96 per patient per week. Although this figure does not include the cost of any other services CREST patients may require it is probably cost effective when compared with the price of £450 per person per week for patients in an independent sector nursing home used by the health authority. In addition, some of the patients attending CREST reduced their use of other community based services. For example, a patient who required help from a district nurse to get up in the morning and to return to bed at night would not need this help when at CREST (Chapter 8, Section 8.4).

The ward in which CREST is currently based is staffed entirely by primary nurses and 'homemakers'. The primary nurses are paid at Grade E and are all qualified registered mental nurses. The homemakers are a new grade of staff whose role encompasses delivering personal care to patients as directed by primary nurses and conducting housekeeping duties. The homemaker role is a development specific to the elderly care team in the Trust and is one reason for the lower cost of care when compared to the independent sector. The development of this role was influenced by the findings of the CREST evaluation, where nursing assistants successfully took on some responsibilities previously considered part of a qualified associated nurse's role.

The mental health unit is in the process of building two, not three, 30-bedded nursing homes which will reflect the long term recommendations made in the CREST report (Figure 10.4). These nursing homes will contain provision for both day and night care as well as long term residential care. This means that patients who have dementia and require nursing assistance will be cared for by the same team throughout their period of care. It is hoped that this will be a positive benefit to patients and their carers.

The evaluation of CREST was designed with the intention that the results would influence future care provision in the health authority.

The information collected in June 1993 indicates that the CREST report assisted managers in making decisions about the long term provision of care for elderly confused people and their carers in the Mental Health Unit.

10.7.3 Future research

There is increasing emphasis on evaluating health care provision within the British system (Audit Commission, 1992; Department of Health, 1993b; St Ledger et al, 1992). The purpose of this kind of research is to contribute to the health and well being of the population by systematically and effectively implementing the results in practice (Department of Health, 1993b). The national strategy for research for health acknowledges that local projects are vitally important if local populations are to have services appropriate to their specific requirements. The Mental Health Unit serves a multi-racial population. Two patients who attended CREST came from Afro-Caribbean descent, the rest were Caucasian. CREST failed to attract patients from the wider multi-racial population. Although this may be because the majority of that population are currently under 65 years of age, it is acknowledged that further research is needed into the needs of the multi-ethnic older population. In particular, it is important to establish whether certain ethnic populations, for example those of Asian descent, would prefer night sitter support rather than CREST.

Further research into the financial cost of total packages of care to individual patients including CREST is needed. It is important to compare the cost of such packages accurately with residential facilities for elderly confused people. In addition, further work on carer choice in the support services they require to assist them in their role is required.

A major national project is being undertaken to establish the types of breaks required by carers in order to continue to cope with looking after elderly confused people in Britain (Levin and Moriarty, 1990). The results of that study, which is being conducted by the National Institute of Social Work on behalf of the Department of Health should be considered before starting further work. Integration of research results collected from both health and social work research is essential in order to develop seamless services for elderly confused people living in their own homes. The CREST results indicate that carers and patients require individualised packages of care similar to those described in the Kent Community Care project (Challis and Davies, 1986). The results of the CREST and Kent projects indicate how important it is for health and social service researchers to work together and learn from each other's work in order to meet best the challenges of caring for elderly people over the next decade.

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MAUDSLEY STANDARDS	APPENDIX 5.1
Standard 1 - The Knowledge Base	Relevant theory and research are used as a basis for decisions regarding nursing practice.
Standard 2 - Patient Involvement	Patients are involved to the full extent of their capabilities in the assessment, planning, implementation and evaluation of their own nursing care.
Standard 3 - Assessment	Comprehensive patient assessment includes physical, psychological and social assessment carried out through interviewing and observations.
Standard 4 - Care Plans	Problem identification, objective setting and a problem solving approach to meeting the needs of patients are used in developing nursing care plans and planning treatment.
Standard 5 - Nursing Interventions	Nursing interventions are designed to promote, maintain or restore mental and physical health and maximum function: a) The activities of daily living are used in a goal directed way in working with patients. b) The environment is structured to establish and maintain a therapeutic milieu c) Knowledge of physical treatments and the clinical skills which are related are used in working with patients. d) Psychological treatments are used to assist patients to achieve their maximum potential.
Standard 6 - Evaluation	Patient responses to nursing interventions are evaluated to determine their effectiveness and revise care plans as necessary.
Standard 7 - Multi-Disciplinary Clinical Teams (MDCT)	Nurses participate as members of multi-disciplinary clinical teams in assessing, planning, implementing and evaluating treatment programmes and care plans.
Standard 8 - Community Service	Nurses participate with other members of the community in planning and policy making for the provision of mental health care, including the promotion of health, prevention of illness, treatment and rehabilitation.
Standard 9 - Health Promotion	Individuals, families and community groups are assisted to achieve satisfying and productive patterns of living through health promotion.
Standard 10 - Education, Training and Development	Nurses participate in supervising the professional and educational development of colleagues and assume responsibility for their own development.
Standard 11 - Research and Innovation	Contributions to nursing practice and health care are made through participation in research, innovation and evaluation of theory and practice.

This model of nursing has as its focus 12 activities of living (ALs). Nursing is perceived as assisting patients as individuals to solve, alleviate, cope with or prevent problems relating to ALs rather than as treating patients with specific disease conditions.

The 12 activities of living are based on a model of living:

1. Maintaining a safe environment
2. Communicating
3. Breathing
4. Eating and drinking
5. Eliminating
6. Personal cleansing and dressing
7. Controlling body temperature
8. Mobilising
9. Working and playing
10. Expressing sexuality
11. Sleeping
12. Dying

The model further includes consideration of:

a) Life-span of living
b) Dependence/independence in living
c) Circumstances affecting living (e.g. housing conditions)

It is stated that activities of living will vary between individuals in terms of:

a) How they are carried out
b) How often they are carried out
c) Where they are carried out
d) When they are carried out
e) Why they are carried out in a particular way
f) What is understood about them
g) What attitude is held towards them

ROPER, LOGAN AND TIERNEY'S MODEL OF NURSING (1985)

The four stages of the nursing process are used when applying the Roper et als model in practice.

ASSESSMENT

Activities of living are assessed as follows:

a) The routine/ways the person normally uses to fulfil activities of living.
b) The extent to which they can fulfil these routines at the time of assessment.

ACTUAL and POTENTIAL problems are then defined

PLANNING

a) Appropriate PATIENT CENTRED GOALS are defined
b) Nursing interventions are planned. They generally embrace 3 types of action:
   PREVENTING
   COMFORTING
   RESPONDING TO PATIENTS SEEKING ACTIVITIES

IMPLEMENTATION

Care is conducted as planned facilitating MAXIMUM PATIENT INDEPENDENCE

EVALUATION

Conducted by evaluating the extent to which patient goals are achieved

ROPER, LOGAN AND TIERNEY'S MODEL OF NURSING (1985)

APPENDIX 6.1

OPERATIONAL POLICY FOR CREST

1. Background

Nurses involved in caring for elderly people are looking towards the future and trying to provide facilities which meet the needs of the community they serve.

This innovative service aims to offer nursing support for elderly people at night on weekdays - Monday to Thursday. It is envisaged that the users will be individuals who have difficulty sleeping at night, who may be noisy and disrupt their carer's sleep. At present, these people are frequently admitted to in-patient care to give carers relief rather than for formal intervention. It is hoped that the Night Hospital will provide sufficient relief to carers without warranting full admission.

Sitting services for elderly confused people have been shown to be effective, in particular with those too frail to travel. A sitter service does, however, have the dual disadvantages of a stranger going into the home for long periods denying carers privacy, and in small homes the noisy confused individual may continue to disrupt carer's sleep. The night hospital service may in many instances, therefore, have advantages over a sitter service.

The service is jointly funded by a Health Authority and the Inner City Partnership for an initial period of 2 years 6 months. During this time a comprehensive evaluation of the night hospital will be conducted and the result of this used to predict whether the service meets the needs of patients and their carers.

2. Aims

To provide, as part of the comprehensive community-orientated mental health services for the District of South East London, support for elderly mentally confused people and their families at night.

To provide relief for relatives who are caring for elderly mentally infirm people at home. The Night Hospital will give the opportunity for relatives to have a night free, allowing them to rest or socialise undisturbed.

To provide individualised programmes of care for each patient at night which are orientated towards facilitating patients' independence and dignity.

To provide a service which supports informal carers by working in partnership with them to deliver quality care to patients.

3. Philosophy of the service

That patients should be able to remain in their own homes for as long as they wish to cared for by relatives and friends who are, in turn, supported by the statutory health services.

When a sitter service is deemed more appropriate, due to a patient's frailty, the night hospital staff will arrange appropriate referrals to voluntary and statutory agencies.

The service will be developed around the individual needs of patients and their families. Each patient will have an individualised treatment programme using a nursing intervention approach, the key objective of the service being to meet the patients' needs.

Nursing staff will be committed to taking a completely realistic approach to patients' needs and be aware of the contribution both statutory and voluntary services can make to their patients' health.

Patients will receive care and treatment in the least restrictive setting with as much freedom as possible.
Patients will have the right to personal privacy.

They will have the right to be addressed with courtesy and respect at all times, and to be addressed as they choose.

4. Referral Procedure

The service will be open to all residents of the area.
An open referral procedure will be adopted. Referral will be accepted from:

Patient's relatives

Community nursing staff

Hospital nursing staff

Community physicians - GPs

Consultant psychiatrists

Social services

Voluntary services

A formal system of assessment will be used to find out which professionals or volunteers are also involved so that liaison can take place.

Each referred patient will be visited at home by a member of the team to assess suitability for attendance. Assessment will normally be conducted in conjunction with other members of the community multi-disciplinary team.

In emergency situations patients may attend the night hospital prior to liaison with other members of the health care team involved in their care, although consultation should take place as soon as possible.

Referrals will only be accepted from the day hospital on the basis of attendance at the night hospital being an alternative, not in addition to attendance during the day.

Referrals should normally be in writing on the appropriate form (A2p) and addressed to the charge nurse.

The Community Psychiatric Nursing Department secretary will receive referrals during the day.

5. Attendance periods

The service will run for 4 nights a week - Monday to Thursday inclusive.

The Hospital will cater for a maximum of 15 per night giving a maximum of 60 places per week.

Patients will be collected by sitting ambulance with a nurse escort between 8.00 p.m. and 9.00 p.m. They will be returned home the following day between 8.00 a.m. and 9.30 a.m.

Patients may be delivered to the hospital between 8.00 p.m. and 9.00 p.m. and collected by 9.30 a.m. by relatives or friends.

Patients will attend for a minimum of one night a week and a maximum of four nights.

Patients' progress will be reviewed on a regular basis. Where the prime aim of attendance is respite care a thorough re-assessment after three months' attendance will be made in conjunction with the multi-disciplinary team and relatives.

6. Accommodation

The service will be placed at the Geriatric Day Unit, South Western Hospital.

Sleeping accommodation will be in the areas marked A.

Z-beds will be screened in area A to provide privacy.

Patients will be encouraged to change in the bathrooms to promote privacy.

The small room A1 will also be used for sleeping accommodation when necessary.

The day room area B will be used for recreational and structured activities.

A small kitchen with toast sandwich maker, cooker and kettle can be used by nurses and patients.

Low level lighting will be used throughout the area, as research demonstrates that fluorescent lighting can further confuse the expected patient group.

7. Programme

Individual assessments will be completed after four nights' attendance using a stress management/activities of living model of nursing.

Individual programmes will be drawn up based on patients' assessment. Most programmes will be aimed at at least one of the following:

(a) Two weekly for those aimed at promoting continence

(b) Four weekly for those aimed at facilitating independence through social activity and/or reducing nocturnal restlessness and promoting sleep.

(c) Four weekly for those aimed at providing respite care. Where the aim is largely orientated towards the carer, attendance will not normally exceed three months.

Light entertainment will be provided for patients, e.g. use of video, television, games, reading material. A hot drink and light snack will be provided before 11.00 p.m. Hot drinks and snacks will be available throughout the night.

Between 11.00 p.m. and midnight depending on individual programmes, patients will either be encouraged to prepare for sleep or involved in appropriate activities. At this juncture, A becomes a quiet sleeping area, and B an area for active patients.

Most patients will be woken at 7.00 a.m. to promote regular sleeping patterns and to ensure that the patients are returned home in time for the hospital to accept day patients. When deemed necessary for an individual, a patient will be left to sleep on until 8.00 a.m. If patients can be collected by a relative/friend they may be left to sleep until 9.30 a.m.

A light breakfast will be prepared and served by nursing staff for patients, in the morning.

8. Managerial organisation

The Community Nursing Manager (Mental Health Unit) will be managerially responsible for the Unit.

9. Staffing

The service will be run by nursing staff compromising:

1	C/N Full time
2	S/N Full time
2	SENs Full time
2	Part time Qualified Nurses
1	Helper

A minimum of three nurses will be on duty until 11.30 p.m. A minimum of two nurses will be on duty 11.30 p.m. to 9.30 a.m. and Porter/Driver on duty from 7.00 p.m. to 9.30 a.m.

Nursing staff rotas will be finalised once the Charge Nurse of the service is appointed. In principle, full time nurses will work a seven night fortnight, 6 x 11 hour and 1 x 9 hour shifts. Part time nurses will work twilight shifts 7.00 p.m. - 11.30 p.m. and 9 hour nights 11.30 p.m. - 9.30 a.m.

All nursing staff should be in post by 1 November 1989.

10. Medical Supervision

Patients will be asked to visit their General Practitioner for non-emergency medical care.

Patients will be referred for psychological medical assessment to the Consultant Psychiatrist (Elderly Mental Health) from the service when appropriate.

11. Admission and Discharge

This will be the responsibility of the clinical nursing team. It will be a service requirement that someone will be at home to receive users in the morning between 8.00 a.m. and 9.30 a.m.

In the event of the above breaking down, the individual patient will be taken to a Day Hospital.

12 Food and Beverages

Supplies will be ordered from and despatched by the Mental Health Unit Catering Department until such time as Mental Health Elderly Services are relocated.

Dry goods will be delivered on a Monday once a week. The Charge Nurse will complete a requisition and send it to the Catering Manager at a London Hospital to arrive not later than the preceding Friday.
Bread, butter, eggs, milk and any other perishable goods deemed necessary will be sent daily from a London Hospital Catering Department.

All supplies sent to the Night Hospital will be so labelled. Nurses will prepare patients' food and beverages in the kitchen.

13 Other Supplies and Stores

These will be ordered from the Mental Health Unit Supplies Department and delivered monthly.

14. Laundry

Will be supplied from and laundered at a London Hospital.
Five Z-beds will be supplied with duvets and appropriate sheeting. Their use will be monitored and an evaluation prepared at six months. The remaining 10 beds will be supplied with sheets and blankets.

All sheeting will be coloured polycotton. The cost of this to be met from the main laundry budget. Sufficient linen will be purchased to supply 60 clean changes a week.

Clear linen will be delivered on Mondays and Wednesdays. Dirty linen will be collected on Wednesdays and Fridays.

Specially marked linen bags will be supplied clearly marked Night Hospital.

A small float of night clothes and dressing gowns will be supplied by the laundry. Generally, however, patients will be expected to bring their own night clothes.

Adequate storage is available for Z-beds and laundry in a large cupboard in the main corridor.

15. Cleaning

Cleaning will be conducted in the morning between 7.30 a.m. and 9.00 a.m. by staff under contract to the Community Unit.

APPENDIX 6.2

HEALTH AUTHORITY

MENTAL HEALTH UNIT

JOB DESCRIPTION

POST TITLE:	Team Leader
GRADE:	Charge Nurse II
RESPONSIBLE TO:	Nursing & Patients Services Manager Community
ACCOUNTABLE TO:	Director of Nursing Service, Mental Health Unit
LOCATION:	A Health Authority, Night Hospital based at South Western Hospital

JOB SUMMARY

1. To develop and provide a comprehensive nursing service for elderly mentally ill people at night.
2. To agree appropriate standards of care with the project evaluator and nurse manager.
3. To collect relevant research data and monitor other nursing staff in this role.
4. To provide and develop in conjunction with the multi-disciplinary team and other relevant agencies a service for clients which takes account of individuals' physical, psychological and social needs.
5. To provide leadership and management of a staff team, including practical involvement with clients.
6. To work in association with the staff team, other professionals, relevant agencies and people significant to clients.

RESPONSIBLE FOR:

1. A defined staff team

MAIN DUTIES AND RESPONSIBILITIES

EVALUATION

1. To participate in the collection of data.
2. Liaise closely with the project evaluator.
3. To ensure relevant research data re collected by all members of the nursing team, as requested by the evaluator.
4. To set structural and process standards for the unit together with the evaluator and manager.
5. To inform the manager and project evaluator if either three or four cannot be conducted.

MANAGERIAL LEADERSHIP

1. Responsibility for the management of a staff team and for devising and implementing a staff rota ensuring most effective use of human resources available.
2. Organisation, co-ordination, support and supervision of staff, resources to provide effective help to individuals which takes account of their strengths as well as their needs within a framework of individualised goal planning.
3. Working jointly and sensitively with clients and staff and ensuring that effective communications exist.
4. Monitoring the performance of the staff.
5. Monitoring and control of human, financial and material resources within an agreed budget and utilisation of those resources for maximum benefit.
6. Providing direction and leadership of the team consistent with the present goals and future pattern of mental health provision.
7. Implementing agreed unit procedures.
8. Participate in interviewing and selecting staff.
9. Co-ordinating annual leave.

PLANNING AND POLICY FORMULATION

1. Participating in the development of policies relevant to the night hospital service from both service and research perspectives.
2. Assessment and monitoring of clients functioning using relevant assessment tools, documentation and presentation of information.

3. Evaluating the quality of service provided from the client's point of view and at facility level.

PERSONAL AND PROFESSIONAL RESPONSIBILITIES

1. Adhering to the UKCC Professional Codes of Conduct.
2. Undertaking regular review of performance with the line manager to agree personal and service goals.
3. Undertaking training in relation to Equal Opportunities Policy of the unit and evaluation responsibilities.
4. Seeking and making use of research findings relevant to the area of work.
5. Supervising the professional work of other nursing staff.
6. Acting as a positive role model for colleagues in relation to personal and professional conduct and practice.

EDUCATION AND TRAINING

1. Undertaking individual performance review with all staff including setting of personal and service goals.
2. Providing an orientation and induction programme for all new staff consistent with the requirements of their role.

LIAISON AND EXTERNAL RELATIONSHIPS

1. Take active steps to project a positive image of the clients and the service.
2. Make and keep active contact with community agencies and establish a network of contacts relevant to the client group.

IN ADDITION

1. Undertake any other duties as appropriate to the grade as designated by the manager.
2. To carry out the duties in line with equal opportunities, respecting the different cultural backgrounds of clients and colleagues.
3. Observe health and safety procedures.
4. Required to regularly drive the night hospital bus, collecting from and returning home clients.

ADDITIONAL INFORMATION

The services run from the hospital site will be moving out into the community and a London Hospital is scheduled to close in a series of planned stages. Some services will be moved from and to other hospital sites in the district as part of the planned relocation of the mental health unit.

All staff are required to work flexibly in response to the developing needs of the services as we achieve our major objective; to provide improved facilities and support for people with mental health problems in South East London. Accordingly this job description will be reviewed with the post holder six months from appointment and at subsequent intervals as necessary. The mental health unit has a positive approach to staff training to meet both the changing needs of the service and individual employee's development.

The unit aims towards maintaining the goodwill and confidence of its own staff and of the general public. To assist in achieving this objective, it is essential that, at all times, employees carry out their duties in a courteous and sympathetic manner.

This project is funded jointly by a Health Authority and the Inner City Partnership for an initial period of two years six months. During this time a comprehensive evaluation of the Night Hospital will be conducted and the results of this used to predict future requirements.

HEALTH AUTHORITY
MENTAL HEALTH UNIT

JOBS IN THE NEW SERVICE

NIGHT HOSPITAL NURSING RESEARCH PROJECT

CHARGE NURSE II
RMN ESSENTIAL - SRN/ENB OR OTHER RELEVANT COURSE DESIRABLE

"Could you be the Charge Nurse in a unique nursing
project - the first of its kind in Europe?"

The night hospital is an innovative new service which will be open on Monday to Thursday nights. Its aim is to reduce stress to informal carers of elderly confused people in addition to promoting independence and delivering quality nursing care to the clients. A full evaluation of the project will be conducted and you will be actively involved in this.

You should have an interest in care of the elderly mentally ill and display good leadership and managerial qualities. In addition, an interest in research and its relevance to nursing is essential. Research supervision will be provided and you will have an opportunity to develop these skills. This post represents an excellent opportunity for professional development.

This project is funded jointly by Health Authority and the Inner City Partnership for an initial period of two years six months. During this time a comprehensive evaluation of the night hospital will be conducted and the results of this used to predict future requirements.

A clean, current driving licence is essential as there is a requirement to drive the night hospital bus.

CLOSING DATE: 17 August 1988
INTERVIEW TIME: 26 August 1988

For Application Form and Job Description contact:

Personnel Department

AN EQUAL OPPORTUNITIES EMPLOYER
THE AUTHORITY THAT CARES

APPENDIX 6.3

HEALTH AUTHORITY

MENTAL HEALTH UNIT

NIGHT HOSPITAL (ASSOCIATE NURSE)

PERSON SPECIFICATION

1. On live register of UKCC
2. Knowledge and understanding of the process of helping people using individual care planning.
3. Interest in elderly people with long term mental health needs.
4. Evidence of awareness of current issues in Mental Health Care.
5. Ability to work as a member of a multi-disciplinary team.
6. Awareness of the application of Mental Health legislation.
7. Awareness of multi-cultural issues and Equal Opportunities.
8. Evidence of a positive attitude towards changes and developments in service provision.
9. Ability to work flexible hours over 24 hours.
10. Evidence of ability to make positive relationships with clients.
11. Ability to work jointly and sensitively with clients and significant others in their lives, other professionals, helpers and relevant agencies to meet the needs of individual clients.
12. Evidence of professional development.
13. Current clean driving licence.

APPENDIX 6.4

CONSENT FORM FOR PARTICIPATION IN RESEARCH PROJECTS AND CLINICAL TRIALS

Title of project: **NIGHT CARE FOR ELDERLY PEOPLE - AN EVALUATION OF A NEW NURSING SERVICE.**

Outline explanation:

I have had the purpose of the research study 'Night Care for Elderly People' explained to me and understand that this research aims to establish the value of CREST (care and respite for elderly people with support and treatment) for elderly confused people and their relatives.

I (name) ____________________________

of (address) ____________________________

____

hereby consent to take part in the above investigation, the nature and purpose of which have been explained to me. Any questions I wished to ask have been answered to my satisfaction. I understand that I may withdraw from the investigation at any stage without necessarily giving a reason for doing so and that this will in no way affect the care my relative/friend receives.

SIGNED (Volunteer) __________________ Date __________

(Interviewer) __________________ Date __________

(Witness, where appropriate) TO BE COMPLETED BY CARER Date __________

APPENDIX 6.5

SEMI-STRUCTURED CARER INTERVIEWS

Question 1

a) Can you describe the feelings you have experienced concerning your friend/relative's attendance at the night hospital?

b) Have you any ideas why you feel the way you do?

Question 2

a) Has the fact that your friend/relative comes to the night hospital changed your day to day life? YES/NO

b) If YES, please describe the change.

Question 3

a) What services were you receiving prior to your friend/relative's attendance at the night hospital:

i) Community psychiatric nurse (CPN)
ii) Social worker
iii) District nurse
iv) Meals on wheels
v) Home help
vi) Other services

b) Has this changed?

APPENDIX 6.6

BIOGRAPHICAL VARIABLES COLLECTED ON CARERS AND PATIENTS

1. Age of patient
2. Sex of patient
3. Diagnosis
4. Who referred the patient to CREST
5. Carer relationship
6. Sex of carer
7. Number of people in household
8. Type of housing/accommodation
9. Reason for discharge

APPENDIX 6.7

REFERRAL FORM:
CREST NIGHT HOSPITAL

Patient's Surname: ....

First Name(s): ....

Address: ....

Telephone No.: ....

Date of Birth: ....

Male/Female/Marital Status: ....

Ward (if in-patient): ....

Carer's Name: ....

Relationship: ....

Address: ....

Telephone No. Home: ....

Work: ....

Patient's GP.: ....

Telephone No.: ....

Address: ....

Other Agencies involved: ....

Presenting Problem/Relevant History/Treatment: ....

....

....

Reason for referral including future plans: ....

....

....

Current Medication: ....

....

Referred by: .... Telephone No.: ....

Signed: .... Date: ....

To be completed by Nurse Assessor

Recommendations: ....

....

Action Taken (specify): ....

....

Signed:................................. Date: ....

APPENDIX 6.8

REVIEW OF CREST PATIENTS NURSING CARE PLANS

	YES	NO
1a) Assessment complete after four nights using the activities of living framework?	☐	☐
b) Is there evidence that the patient's carer was involved in the assessment?	☐	☐
2a) Is there evidence that individualised care plan had been constructed within the patients first two weeks of attendance?	☐	☐
b) Is there specific reference made to patient orientated goals concerning:		
i) Promoting patient independence in at least one activity of living?	☐	☐
ii) Promoting continence?	☐	☐
iii) Reducing nocturnal restlessness and promoting sleep?	☐	☐
iv) Facilitating independence through social activities?	☐	☐
v) Planning care specifically in response to carers request? If so give details:-	☐	☐

3a) <u>Evaluation of programmes</u>.
How often was the care plan reviewed?

Weekly ☐

Every fortnight ☐

Monthly ☐

Less frequently ☐
If so why?

	YES	NO
b) Is there evidence that care was reviewed in conjunction with carers?	☐	☐
4 Is there evidence that the patient was allocated a primary nurse who took responsibility for assessing, planning, implementing and evaluating care?	☐	☐

APPENDIX 7.1

POLICY ON THE SUPPLY, STORAGE AND ADMINISTRATION OF MEDICINES AT CREST

1. Provision of Medicines

1.1 Medicines will normally be prescribed by each patient's GP, and dispensed by a retail pharmacist.

1.2 Medicines prescribed and dispensed from a hospital to a patient as an out-patient will be treated as though prescribed by a GP and dispensed by a retail pharmacist.

1.3 Medicines will be brought in by patients and these will be the source of supply. (Medicines will remain the property of the patient.)

1.4 Whenever medicines are supplied in this way, staff must ensure that containers are properly labelled with:

a) The name of the patient.
b) The name and strength of the preparation.
c) The full instructions (not "as directed").
d) The name and address of the dispensing pharmacy.
e) The date dispensed which must be within the last three months.

2. Storage

2.1 To avoid loss and accidental self medication by other patients, medicines must be kept in a secure place.

3. Administration and Recording

Patients who have their own medicines for self administration should continue this practice whilst at CREST. Some patients may need the assistance of a relative whilst at home. In this instance, the night hospital would take this role.

On assessment for admission to CREST it would be advantageous if the following details on medication are noted. This will ensure that details are obtained during normal working hours. They would be recorded on a card or part of the nursing records attached to a record of administration:

a) Name and date of birth of patient.

b) Details of drug sensitivity (if known).

d) Full details, including name, date prescribed, quantity, dose, strength and route of administration of each medicine.

e) Times at which medicines should be administered.

4. Record of Administration

Following the administration of medicines as per the normal procedures, a record of administration by nursing staff/self administration should be made. A medication record chart similar to in-patient cards should be used.

APPENDIX 7.2

GRADE	G		E		D		C		A	
TIME OBSERVED	3h 30m		5h 20m		26h 50m		13h 20m		1h 40m	
	CLINICAL									
	freq.	% of Time	freq.	% of Time	freq.	% of Time	freq.	% of Time	freq.	% of Time
Social Conversation			1	3.1	5	3.1	5	6.3	2	20
Purposeful therapeutic interaction	1	4.8	2	6.3	15	9.3	8	10.0	1	10.0
Conducts individual behavioural programme					1	0.6				
Delivers or prepares physical treatment / medication					4	2.5	2	2.5		
Assists with dress/ undressing			1	3.1	6	3.7	1	1.3		
Assists with eating										
Assists with hygiene	1	4.8	1	3.1	3	1.9	1	1.3		
Assists with toileting					13	8.1	8	10.0		
Assists with preparation for sleep	1	4.8	1	3.1	4	2.5	5	6.3		
Assists with mobility					4	2.5	1	1.3		
Observation					4	2.5				
Recreation with patient - individual							1	1.3		
Recreation with patient - group										
Conducts formal reality orientation programme										
Collects patient from home (Driving)	3	14.3			13	8.1	4	5.0		
Takes patient home (Driving)					2	1.2			6	60.0
Communication with relative / friend at CREST					7	4.3	1	1.3		
Communicates with relative/friends in their own home	2	9.5			2	1.2	4	5.0		

RESULTS FROM NON-PARTICIPANT OBSERVATION OF NURSING ACTIVITY: PERIOD 1

APPENDIX 7.2

GRADE	G		E		D		C		A	
TIME OBSERVED	3h 30m		5h 20m		26h 50m		13h 20m		1h 40m	
	CLINICAL									
	freq.	**% of Time**	**freq.**	**% of Time**	**freq.**	**% of Time**	**freq.**	**% of Time**	**freq.**	**% of Time**
Reviews individual patients nursing needs/care plans			4	12.5	8	5.0	1	1.3		
Receives records & gives clinical report verbal/ written										
Monitors patients sleep			12	37.5	11	6.8	9	11.3		
Communications re patients on phone										
Other					8	5.0	3	3.8		
Total Frequency Time Clinical	8	38.1	22	68.8	110	68.3	54	67.5	9	90.0

GRADE	G		E		D		C		A	
TIME OBSERVED	3h 30m		5h 20m		26h 50m		13h 20m		1h 40m	
	NON-CLINICAL									
	freq.	**% of Time**	**freq.**	**% of Time**	**freq.**	**% of Time**	**freq.**	**% of Time**	**freq.**	**% of Time**
Time with other h/c workers liaising/ communicating	2	9.5	3	9.4	34	21.1	16	20.0		
Domestic work bedstripping/making	1	4.8	2	6.3	4	2.5	5	6.3		
Nursing staff interaction incl. teaching	2	9.5			3	1.9				
Reading/studying										
Research data collection	8	38.1								
Personal time (as distinct from official breaks)			5	15.6	5	3.1	1	1.35	1	10.0
Admin/other duties					5	3.1	4	5.0		
Total Frequencies	13	61.9	10	31.2	51	31.7	26	32.5	1	10.0
Overall Total	21	100.0	32	100.0	161	100.0	80	100.0	10	100.0

RESULTS FROM NON-PARTICIPANT OBSERVATION OF NURSING ACTIVITY:
PERIOD 1

APPENDIX 7.2

GRADE	G		E		D		A	
TIME OBSERVED	4h 40m		10h 10m		42h 10m		1h 50m	
	CLINICAL							
	freq.	**% of Time**	**freq.**	**% of Time**	**freq.**	**% of Time**	**freq.**	**% of Time**
Social Conversation	2	7.1	1	1.6	5	2.0	1	9.1
Purposeful therapeutic interaction	4	14.3	6	9.8	20	7.9		
Conducts individual behavioural programme								
Delivers or prepares physical treatment / medication					1	0.4		
Assists with dress / undressing					7	2.8		
Assists with eating	1	3.6			6	2.4		
Assists with hygiene					7	2.8		
Assists with toileting	2	7.1	3	4.9	7	2.8		
Assists with preparation for sleep			1	1.6	7	2.8		
Assists with mobility	1	3.6	3	4.9	5	2.0	1	9.1
Observation								
Recreation with patient - individual					2	0.8		
Recreation with patient - group					1	0.4		
Conducts formal reality orientation programme								
Collects patient from home (Driving)	1	3.6	2	3.3	13	5.1		
Takes patient home (Driving)					1	0.4	5	45.5
Communication with relative / friend at CREST			5	8.2	2	0.8		
Communicates with relative/friends in their own home	3	10.7	3	4.9	8	3.2		

RESULTS FROM NON-PARTICIPANT OBSERVATION OF NURSING ACTIVITY:
PERIOD 2

APPENDIX 7.2

GRADE	G		E		D		A	
TIME OBSERVED	4h 40m		10h 10m		42h 10m		1h 50m	
	freq.	% of Time	freq.	% of Time	freq.	% of Time	freq.	% of Time
	CLINICAL							
Reviews individual patients nursing needs/care plans					8.0	3.2		
Receives records & gives clinical report verbal/ written					1.0	0.4		
Monitors patients sleep			20.0	32.8	41.0	16.2		
Communications re patients on phone								
Other					1.0	0.4	1.0	9.1
Total Frequency Time Clinical	14.0	50.0	44.0	72.1	143.0	56.5	8.0	72.7

GRADE	G		E		D		A	
TIME OBSERVED	4h 40m		10h 10m		42h 10m		1h 50m	
	NON-CLINICAL							
	freq.	% of Time	freq.	% of Time	freq.	% of Time	freq.	% of Time
Time with other h/c workers liaising/ communicating	10	35.7	4	6.6	48	19.0	2	18.2
Domestic work bedstripping/making	2	7.1	3	4.9	18	7.1		
Nursing staff interaction incl. teaching	2	7.1			3	1.2		
Reading/studying								
Research data collection								
Personal time (as distinct from official breaks)			5	8.2	26	10.3	1	9.1
Admin/other duties			5	8.2	15	5.9		
Total Frequencies Non-Clinical	14	50.0	17	27.9	110	43.5	3	27.3
Overall Total	28	100.0	61	100.0	253	100.0	11	100.0

RESULTS FROM NON-PARTICIPANT OBSERVATION OF NURSING ACTIVITY: PERIOD 2

APPENDIX 7.2

GRADE	**G**		**D**		**A**	
TIME OBSERVED	8h 40m		26h		43h 20m	
	CLINICAL					
	freq.	**% of Time**	**freq.**	**% of Time**	**freq.**	**% of Time**
Social Conversation			6	3.8	1	0.4
Purposeful therapeutic interaction	3	5.8	12	7.7	17	6.5
Conducts individual behavioural programme			2	1.3		
Delivers or prepares physical treatment / medication	1	1.9	3	1.9	1	0.4
Assists with dress / undressing			3	1.9	13	5.0
Assists with eating			7	4.5	3	1.2
Assists with hygiene	8	15.4	5	3.2	5	1.9
Assists with toileting	3	5.8	2	1.3	7	2.7
Assists with preparation for sleep	2	3.8	8	5.1	9	3.5
Assists with mobility			12	7.7	22	8.5
Observation			1	0.6	26	10.0
Recreation with patient - individual						
Recreation with patient - group					1	0.4
Conducts formal reality orientation programme						
Collects patient from home (Driving)	4	7.7	22	14.1	26	10.0
Takes patient home (Driving)			6	3.8	21	8.1
Communication with relative / friend at CREST						
Communicates with relative/friends in their own home			3	1.9	12	4.6

RESULTS FROM NON-PARTICIPANT OBSERVATION OF NURSING ACTIVITY: PERIOD 3

APPENDIX 7.2

GRADE	G		D		A	
TIME OBSERVED	8h 40m		26h		43h 20m	
	CLINICAL					
	freq.	% of Time	freq.	% of Time	freq.	% of Time
Reviews individual patients nursing needs/care plans	5	9.6	5	3.2		
Receives records & gives clinical report verbal/ written			3	1.9		
Monitors patients sleep	9	17.3	24	15.4	31	11.9
Communications re patients on phone						
Other			2	1.3	2	0.8
Total Frequency Time Clinical	35	67.3	126	80.8	197	76.8

GRADE	G		D		A	
TIME OBSERVED	8h 40m		26h		43h 20m	
	NON-CLINICAL					
	freq.	% of Time	freq.	% of Time	freq.	% of Time
Time with other h/c workers liaising/ communicating	4	7.7	8	5.1	12	4.6
Domestic work bedstripping/making	3	5.8	8	5.1	21	8.1
Nursing staff interaction incl. teaching						
Reading/studying						
Research data collection	2	3.8	7	4.5		
Personal time (as distinct from official breaks)	1	1.9			27	10.4
Admin/other duties	7	13.5	7	4.5	3	1.2
Total Frequencies	17	32.7	30	19.2	63	24.2
Overall Total	52	100.0	156	100.0	260	100.0

RESULTS FROM NON-PARTICIPANT OBSERVATION OF NURSING ACTIVITY: PERIOD 3

APPENDIX 8.1

PATIENT NUMBER	INITIALS	AGE	SEX	RELATIONSHIP TO CARER	DIAGNOSIS	SOURCE OF REFERRAL
1	MR T.D	79	M	Husband	Alzheimers	D/N
2	MR B.H.	85	M	Brother	Alzheimers	Day Centre Staff
3	MR A.P.	87	M	Husband	MID	D/N
4	MR B.G.	79	M	Husband	Alzheimers	D/N
5	MRS G.N.	73	F	Landlady	Alzheimers	Age Concern
6	MRS M.L.	91	F	Mother	CVA/MID	Psycho-Geriatrician
7	MR F.F.	62	M	Husband	MID	D/N
8	MRS P.T.	94	F	No Immediate care - lived alone	No Clear Diagnosis	Social Worker
9	MRS M.B.	95	F	Mother	Alzheimers	D/N
10	MRS N.S.	76	F	Wife	MID	GP
11	MRS E.P.	88	F	Wife	Alzheimers	GP
12	MR S.B.	84	M	Husband	Alzheimers	
13	MR N.B.	80	M	Husband	No Clear Diagnosis	Consultant Psychiatrist
14	MR C.L.	80	M	Husband	Alzheimers	D/N
15	MR J.V.	76	M	Father	Alzheimers	D/N
16	MR J.F.	82	M	Husband	Parkinsons	Social Worker
17	MR F.B.	74	M	Husband	MID	Day Centre Manager

INDIVIDUAL PATIENTS BIOGRAPHICAL DETAILS ON ADMISSION, AGE, SEX, DIAGNOSIS, CARER RELATIONSHIP AND SOURCE OF REFERRAL TO CREST

APPENDIX 8.1

PATIENT NUMBER	INITIALS	AGE	SEX	RELATIONSHIP TO CARER	DIAGNOSIS	SOURCE OF REFERRAL
18	MRS V.H.	81	F	Mother	Alzheimers	Day Centre Manager
19	MRS G.B.	79	F	Wife	MID	D/N
20	MRS L.A.	65	F	Mother	Alzheimers	CPN
21	MRS E.W.	90	F	Mother	Alzheimers	Son
22	MR S.F.	68	M	Husband	Alzheimers	Day Centre Manager
23	MRS S.SZ	84	F	Mother	Alzheimers and CVA	Day Hospital Nurse
24	MRS L.M.	86	F	Mother	MID	Day Centre Manager
25	MR M.S.	68	M	Husband	MID	Day Centre Manager
26	MR H.T.	77	M	Husband	No Clear Diagnosis	D/N
27	MR D.G.	84	M	Husband	Alzheimers	Elderly Care Ward
28	MRS M.T.	57	F	Wife	MID	D/N
29	MR E.B.	72	M	No Relation	Alzheimers	Warden
30	MRS K.D.	64	F	Wife	Alzheimers	Husband
31	MRS L.S.	76	F	Wife	Alzheimers	D/N
32	MRS M.N.	79	F	Wife	No Clear Diagnosis	GP
33	MRS E.Y.	84	F	Wife	MID	Husband
34	MR K.B.	81	M	Husband	Alzheimers	D/N

INDIVIDUAL PATIENTS BIOGRAPHICAL DETAILS ON ADMISSION, AGE, SEX, DIAGNOSIS, CARER RELATIONSHIP AND SOURCE OF REFERRAL TO CREST

APPENDIX 8.2

PTNT NO.	NO.OF NIGHTS PER WEEK AT CREST	NO. OF WEEKS	RESPITE CARE	IN-PATIENT	DAY CARE (DAYS)	OUTCOME
1	Varied 1	26	8 - 13	--		REFUSED
2	3	22	6 - 11	22		DIED
3	2	25	21 - 24 due to wife's illness			WIFE DIED LONG TERM CARE
4	4	44	5 + 6 14 + 15 25 + 26 32 + 33			PRIVATE NURSING HOME
5	Up to 3 Irregular	78	31 - 32		2	STILL ATTENDING SPASMODICALLY AT TWO YEARS
6	4	15	--	13 - 15	--	LONG TERM CARE IN-PATIENT
7	4	36	--	20 - 35 THEN DIED	2	DIED
8	3	1	--	--	--	REFUSED (DISCHARGED HOME)
9	4	51	16 + 17 25 + 26 44 + 45	--	--	DIED
10	3	136	35 - 37	--	2	DIED AT HOME - ATTENDED CREST FOR 136 WEEKS
11	4	8	3 - 8	--	2	HUSBAND DIED PART III
12	2 to week 20 3 from week 34	66	20 + 21 32 - 34 45 - 48	7 + 8	--	EVENTUALLY DISCHARGED HOME TOO FRAIL TO ATTEND. SITTER SERVICE ARRANGED.
13	1	26	--	--	--	LONG TERM CARE
14	2	19	--	13 - 18	--	DISCHARGED TO PRIVATE NURSING HOME
15	4	26	--	--	--	DID NOT ATTEND AFTER 18 WEEKS REFUSED AND BETTER SLEEPING PATTERN
16	4	8	--	2 - 8 REHAB	--	DISCHARGED HOME (PARKINSON'S IMPROVED)
17	3	11	--	6 - 7 10 - 11 DIED	2	DIED

INDIVIDUAL PATIENTS ATTENDANCE PATTERNS
AT CREST AND REASONS FOR DISCHARGE

APPENDIX 8.2

PTNT NO.	NO.OF NIGHTS PER WEEK AT CREST	NO. OF WEEKS	RESPITE CARE	IN-PATIENT	DAY CARE (DAYS)	OUTCOME
18	4	28	5 + 6 10 - 12	--	4	PRIVATE NURSING HOME
19	3	48	--	15 38 - 47	2	DIED
20	4	16	8 - 15 DUE TO CARERS ILLNESS	--	4	HOME - CARER BETTER
21	1	6	2 - 6 DUE TO CARERS ILLNESS	--	--	PRIVATE NURSING HOME - CARER ILL
22	2	1	--	--	--	REFUSED
23	3/4	32	23 - 27	3 - 4, 12, 32 DIED	2	DIED
24	3/4	26	--	12 - 14 19 - 23	4	PRIVATE NURSING HOME
25	4	21	--	8 - 10	5	FAMILY PROBLEMS
26	4	14	4 - 7	10 - 14	2	DIED
27	4	46	20 - 22 29 - 31 37 - 38 43 - 44	--	--	LONG STAY CARE
28	4	8	--	4 - 8 DIED	--	DIED
29	4	6	--	4 - 6 REHAB	--	BETTER (PHYSICAL PROBLEMS)
30	2	12	--	--	2	REFUSED
31	3	12	--	3 - 7	--	LONG TERM CARE
32	2	1	--	--	--	PRIVATE NURSING HOME
33	1 2	32	10 - 14	--	2	PRIVATE NURSING HOME
34	3	4	3 - 4	--	--	DISCHARGED HOME

INDIVIDUAL PATIENTS ATTENDANCE PATTERNS AT CREST AND REASONS FOR DISCHARGE

APPENDIX 8.3

Patient Number	1	2	3	4	5	6		TOTAL
Length of time patient observed	12h	10h	11h 50m	12h 10m	11h 30m	12h 10m	Total time obs.	69h 20m 416
Frequencies of observation (every 10 minutes)	72	60	71	73	69	73	Total nos of freq.	% of total time
AD Assist with dressing/ undressing	1	1	1	2	0	0	5	1.20
AE Assist with eating	1	0	1	1	0	0	3	0.72
AH Assist with hygiene	2	1	3	1	1	4	12	2.88
AM Assist with mobility	1		5	2	2	1	11	2.64
AT Assist with toileting	6	1	1	1	0	6	15	3.61
AS Assist with prep. for sleep	2	2	0	3	1	0	8	1.92
BP Behavioural problem ie, shouting	0	0	0	0	0	0	0	0
SC Self contained behaviour	10	1	10	14	9	15	59	14.18
I Independent behaviour ie dressing / eating/ sleeping	2	2	4	3	6	5	22	5.29
IB Individual behavioural prog. being conducted	0	3	0	1	0	0	4	0.96
IN Interacting with nurse	7	4	5	10	1	3	30	7.21
IP Interacting with other patients	0	0	0	1	2	3	6	1.44
NESC Nurse encouraging self care	1	1	0	0	3	0	5	1.20
NR Recreation with nurse	1	2	0	0	0	0	3	0.72
PR Recreation / interaction with other patients	0	0	0	0	0	0	0	0
ROG Reality orientation group	0	0	2	2	0	0	4	0.96
RPC Receives physical care / check ie wound/ pressure area/medication	0	1	1	2	0	1	5	1.20
S Sleeping	38	41	38	30	44	35	224	53.85

RESULTS FROM NON-PARTICIPANT OBSERVATION OF PATIENT ACTIVITY - PERIOD 1

APPENDIX 8.3

Patient Number	1	2	3 162.	4	5	6	TOTAL	
Length of time patient observed	13h	12h 10m	12h	11h 40m	11h 20m	11h	Total time obs.	71h 10m 427
Frequencies of observation (every 10 minutes)	78	73	72	70	68	66	Total nos of freq.	% of total time
AD Assist with dressing/ undressing	0	0	4	1	1	1	7	1.64
AE Assist with eating	2	0	3	0	0	0	5	1.17
AH Assist with hygiene	0	0	1	1	0	0	2	0.47
AM Assist with mobility	7	3	4	3	0	0	17	4.00
AT Assit with toileting	2	3	0	0	3	1	9	2.10
AS Assist with prep. for sleep	2	2	1	0	1	2	8	1.87
BP Behavioural problem ie shouting	20	2	0	0	10	0	32	7.49
SC Self contained behaviour	15	12	10	9	5	8	59	13.81
I Independent behaviour ie dressing/eating/ sleeping	3	4	1	2	3	2	15	3.51
IB Individual behavioural prog. being conducted	0	0	0	0	0	0	0	0
IN Interacting with nurse	5	4	2	11	10	0	32	7.49
IP Interacting with other patients	0	0	0	0	0	0	0	0
NESC Nurse encouraging self care	0	0	0	1	3	0	4	0.94
NR Recreation with nurse	0	0	0	0	2	0	2	0.47
PR Recreation/ interaction with other patients	0	0	0	0	0	0	0	0
ROG Reality orientation group	0	0	0	0	0	0	0	0
RPC Receives physical care /check ie wound/ pressure area/medication	0	0	0	0	1	3	4	0.47
S Sleeping	22	43	46	42	29	49	231	54.1

RESULTS FROM NON-PARTICIPANT OBSERVATION OF PATIENT ACTIVITY - PERIOD 2

APPENDIX 8.3

Patient Number	1	2	3	4	5	6	TOTAL	
Length of time patient observed	15h 50m	12h 30m	12h 30m	12h 20m	13h 50m	15h 20m	Total time obs.	82h 10m 493
Frequencies of observation (every 10 minutes)	95	75	75	74	83	91	Total nos of freq.	% of total time
AD Assist with dressing/ undressing	1	0	1	1	1	1	5	1.01
AE Assist with eating	0	0	0	0	0	1	1	0.20
AH Assist with hygiene	2	2	2	0	0	0	6	1.22
AM Assist with mobility	0	1	3	5	0	5	14	2.83
AT Assit with toileting	2	0	2	2	0	0	6	1.22
AS Assist with prep. for sleep	1	2	1	2	1	0	7	1.42
BP Behavioural problem ie shouting	3	0	0	4	1	4	12	2.43
SC Self contained behaviour	7	2	11	21	13	30	84	17.04
I Independent behaviour ie dressing / eating/ sleeping	5	15	20	8	5	3	56	11.36
IB Individual behavioural prog. being conducted	0	0	0	0	0	0	0	0
IN Interacting with nurse	13	7	1	4	9	0	34	6.9
IP Interacting with other patients	8	1	0	0	4	2	15	3.04
NESC Nurse encouraging self care	0	0	0	0	0	0	0	0
NR Recreation with nurse	0	2	0	1	2	0	5	1.01
PR Recreation/ interaction with other patients	0	0	0	0	0	0	0	0
ROG Reality orientation group	0	0	0	0	0	0	0	0
RPC Receives physical care / check ie wound/ pressure area/ medication	1	0	0	0	0	0	1	0.2
S Sleeping	52	43	34	26	47	45	247	50.1

RESULTS FROM NON-PARTICIPANT OBSERVATION OF PATIENT ACTIVITY - PERIOD 3

APPENDIX 8.4

Patient Number	GETS ABOUT / CONFINED TO BED	NEVER CONFUSED / LOST	HELPFUL / DIFFICULT	CONVERSATION	FEEDING	DRESSING	SLEEPING	URINARY CONTINENCE	RESTLESS	MOOD	Visual Analogue Scale **TOTALS**
1	73	43	76	42	41	82	66	67	45	80	615
2	23	100	52	100	25	24	49	82	81	49	585
3	96	4	30	12	0	92	61	34	8	57	394
4	96	90	37	95	7	95	27	93	6	41	587
5	47	47	47	23	0	9	47	7	47	77	351
6	92	27	12	28	1	23	84	74	63	28	432
7	88	25	26	27	27	87	0	55	6	6	347
8						NO DATA					
9	100	75	58	86	51	100	50	39	32	68	659
10	69	20	57	18	22	81	89	22	71	29	478
11	1	29	57	76	1	16	19	36	19	50	304
12	13	100	90	97	97	97	25	84	15	83	701
13						NO DATA					
14	24	16	0	0	0	20	50	29	0	0	139
15	80	46	47	18	13	94	80	10	48	44	480
16	94	11	54	4	3	98	54	2	13	72	405
17						NO DATA					

PATIENT DEPENDENCE DATA COLLECTED BY NURSES WITHIN ONE WEEK OF ADMISSION: TIME A

APPENDIX 8.4

Patient Number	GETS ABOUT/ CONFINED TO BED	NEVER CONFUSED/ LOST	HELPFUL/ DIFFICULT	CONVERSATION	FEEDING	DRESSING	SLEEPING	URINARY CONTINENCE	RESTLESS	MOOD	Visual Analogue Scale TOTALS
18	17	62	48	19	18	67	84	18	85	34	452
19	68	82	52	57	2	80	15	85	16	15	472
20	88	5	51	5	4	66	5	3	4	5	236
21	78	14	27	9	1	80	33	15	1	26	284
22	21	21	22	32	0	59	29	69	74	39	366
23	45	59	56	86	11	39	80	4	76	70	526
24	36	19	34	6	5	19	82	3	17	11	232
25	53	51	40	39	37	49	26	100	10	10	415
26	25	44	51	54	10	88	71	69	56	48	516
27	29	18	1	1	0	99	30	31	1	0	210
28	100	21	61	0	0	70	11	0	0	66	329
29	5	6	7	4	5	92	6	5	19	5	154
30	92	44	24	6	4	48	42	100	73	51	484
31	100	70	18	29	80	100	68	100	17	15	597
32	4	5	5	3	3	42	4	3	4	5	78
33	21	49	11	1	0	0	25	1	1	20	129
34	98	44	96	3	96	97	63	97	45	96	735

PATIENT DEPENDENCE DATA COLLECTED BY NURSES WITHIN ONE WEEK OF ADMISSION: TIME A, n=31

APPENDIX 8.4

Patient Number	GETS ABOUT / CONFINED TO BED	NEVER CONFUSED / LOST	HELPFUL / DIFFICULT	CONVERSATION	FEEDING	DRESSING	SLEEPING	URINARY CONTINENCE	RESTLESS	MOOD	Visual Analogue Scale **TOTALS**
1	72	28	51	50	11	69	65	90	32	76	544
2	0	72	26	90	0	49	38	50	36	51	412
3	98	3	0	5	3	91	94	20	11	24	349
4	30	32	35	34	0	96	22	96	4	72	421
5	50	49	49	11	0	32	51	22	23	69	356
6	93	0	13	0	1	12	23	0	1	0	143
7	50	9	10	11	10	82	9	17	6	21	225
8						DISCHARGED					
9	100	87	74	100	67	100	21	28	48	50	675
10	92	8	57	0	12	100	100	2	89	69	529
11	0	100	27	100	18	100	17	27	25	0	414
12	93	96	96	100	94	100	27	96	21	29	752
13						NO DATA					
14	24	19	0	0	0	25	44	1	17	19	149
15	99	15	99	12	1	86	23	96	33	50	514
16	15	3	15	0	0	16	33	2	27	21	132
17						NO DATA					

PATIENT DEPENDENCE DATA COLLECTED BY NURSES
SIX WEEKS AFTER INITIAL ATTENDANCE: TIME B

Patient Number	GETS ABOUT/ CONFINED TO BED	NEVER CONFUSED/ LOST	HELPFUL/ DIFFICULT	CONVERSATION	FEEDING	DRESSING	SLEEPING	URINARY CONTINENCE	RESTLESS	MOOD	Visual Analogue Scale TOTALS
18	15	28	29	14	14	69	88	13	56	57	383
19	69	75	62	46	1	93	59	65	31	41	542
20	89	14	41	7	4	83	12	15	10	12	287
21					NO DATA						
22					DISCHARGED						
23	9	57	73	84	1	70	56	62	39	64	515
24	19	80	29	49	2	2	59	3	33	38	314
25	46	21	20	33	15	84	11	100	13	15	358
26	25	56	41	66	40	85	36	57	46	40	492
27	79	48	25	49	1	80	0	24	1	28	335
28					NO DATA						
29					NO DATA						
30	49	48	29	20	0	81	24	70	1	31	353
31	100	34	81	15	51	100	35	100	0	77	593
32					DISCHARGED						
33					NO DATA						
34					DISCHARGED						

PATIENT DEPENDENCE DATA COLLECTED BY NURSES

SIX WEEKS AFTER INITIAL ATTENDANCE: TIME B, n=24

APPENDIX 8.4

Patient Number	GETS ABOUT / CONFINED TO BED	NEVER CONFUSED / LOST	HELPFUL / DIFFICULT	CONVERSATION	FEEDING	DRESSING	SLEEPING	URINARY CONTINENCE	RESTLESS	MOOD	Visual Analogue Scale TOTALS
1	NO DATA										
2	1	90	67	66	1	52	53	83	75	74	562
3	100	17	56	15	0	100	10	70	4	10	382
4	86	37	37	52	0	40	4	87	75	44	462
5	26	50	50	8	0	9	28	29	28	77	305
6	93	69	55	48	13	42	45	24	44	64	497
7	68	74	50	29	9	81	25	51	20	10	417
8	DISCHARGED										
9	100	26	59	48	0	100	21	23	23	73	473
10	71	15	30	24	4	91	73	28	50	32	418
11	DISCHARGED										
12	69	86	63	92	91	100	27	73	31	43	675
13	DISCHARGED										
14	27	19	54	0	0	31	30	55	26	26	268
15	NO DATA										
16	DISCHARGED										
17	DISCHARGED										

PATIENT DEPENDENCE DATA COLLECTED BY NURSES
12 WEEKS AFTER INITAL ATTENDANCE: TIME C

APPENDIX 8.4

Patient Number	GETS ABOUT / CONFINED TO BED	NEVER CONFUSED / LOST	HELPFUL / DIFFICULT	CONVERSATION	FEEDING	DRESSING	SLEEPING	URINARY CONTINENCE	RESTLESS	MOOD	Visual Analogue Scale TOTALS
18	13	35	37	36	12	57	11	25	62	59	347
19	63	75	83	77	4	92	55	76	65	59	649
20	58	6	0	0	0	69	14	0	0	13	160
21					DISCHARGED						
22					DISCHARGED						
23	56	74	58	80	2	56	61	64	53	64	568
24	70	56	59	62	0	3	49	5	46	63	413
25	74	54	53	24	18	74	12	22	13	15	359
26					NO DATA						
27	88	50	14	34	0	100	22	49	11	50	418
28					DISCHARGED						
29					DISCHARGED						
30	64	21	25	0	0	68	18	30	1	23	250
31					NO DATA						
32					DISCHARGED						
33					NO DATA						
34					DISCHARGED						

PATIENT DEPENDENCE DATA COLLECTED BY NURSES
12 WEEKS AFTER INITIAL ATTENDANCE: TIME C, n=18

APPENDIX 8.4

Patient Number	GETS ABOUT / CONFINED TO BED	NEVER CONFUSED / LOST	HELPFUL / DIFFICULT	CONVERSATION	FEEDING	DRESSING	SLEEPING	URINARY CONTINENCE	RESTLESS	MOOD	Visual Analogue Scale TOTALS
1	50	49	48	48	21	100	11	33	1	25	386
2	DISCHARGED										
3	DISCHARGED										
4	39	70	75	60	6	87	25	92	69	90	613
5	49	32	51	1	0	26	26	100	0	26	311
6	DISCHARGED										
7	92	23	52	82	75	91	10	50	11	17	503
8	DISCHARGED										
9	100	59	60	79	20	100	19	35	14	38	524
10	91	0	41	0	3	89	91	4	37	8	364
11	DISCHARGED										
12	57	71	80	83	83	91	59	88	65	56	733
13	DISCHARGED										
14	DISCHARGED										
15	83	35	24	0	1	49	21	21	0	31	265
16	DISCHARGED										
17	DISCHARGED										

PATIENT DEPENDENCE DATA COLLECTED BY NURSES
SIX MONTHS AFTER INITIAL ATTENDANCE: TIME D

Patient Number	GETS ABOUT/ CONFINED TO BED	NEVER CONFUSED/ LOST	HELPFUL/ DIFFICULT	CONVERSATION	FEEDING	DRESSING	SLEEPING	URINARY CONTINENCE	RESTLESS	MOOD	Visual Analogue Scale TOTALS
18	9	69	34	22	0	20	19	19	65	30	287
19	81	74	75	63	3	96	78	75	80	65	690
20						DISCHARGED					
21						DISCHARGED					
22						DISCHARGED					
23						NO DATA					
24	6	39	54	75	6	37	10	46	46	92	411
25						DISCHARGED					
26						DISCHARGED					
27						NO DATA					
28						DISCHARGED					
29						DISCHARGED					
30						DISCHARGED					
31						DISCHARGED					
32						DISCHARGED					
33						NO DATA					
34						DISCHARGED					

PATIENT DEPENDENCE DATA COLLECTED BY NURSES
SIX MONTHS AFTER INITIAL ATTENDANCE: TIME D, n=11

APPENDIX 8.5

Patient Number	GETS ABOUT / CONFINED TO BED	NEVER CONFUSED / LOST	HELPFUL / DIFFICULT	CONVERSATION	FEEDING	DRESSING	SLEEPING	URINARY CONTINENCE	RESTLESS	MOOD	Visual Analogue Scale TOTALS
1	75	49	50	51	5	95	21	50	23	31	450
2	32	90	89	88	46	76	75	98	89	70	753
3	93	48	78	79	20	95	49	95	5	71	633
4	78	76	62	88	80	98	94	99	78	57	810
5	97	0	72	71	17	96	72	94	48	49	616
6	98	16	15	13	16	95	84	8	16	19	380
7	91	82	80	63	37	93	47	95	90	40	718
8						NO DATA					
9	94	95	95	95	48	95	77	95	93	86	873
10	52	23	25	24	39	93	83	3	50	5	397
11	82	87	87	90	30	24	50	72	93	80	695
12	91	93	92	96	94	96	92	95	81	88	918
13	4	96	97	98	9	9	75	51	98	97	634
14	51	52	97	21	3	52	97	56	10	32	471
15	97	24	4	5	25	97	71	50	50	20	443
16	47	6	46	3	4	11	14	5	11	12	159
17	97	67	68	83	39	96	65	3	59	82	659

PATIENT DEPENDENCE DATA COLLECTED BY CARERS WITHIN ONE WEEK OF ADMISSION: TIME A

APPENDIX 8.5

Patient Number	GETS ABOUT / CONFINED TO BED	NEVER CONFUSED / LOST	HELPFUL / DIFFICULT	CONVERSATION	FEEDING	DRESSING	SLEEPING	URINARY CONTINENCE	RESTLESS	MOOD	Visual Analogue Scale TOTALS
18	2	72	26	5	4	95	49	17	85	5	360
19	21	47	47	69	7	93	49	77	78	19	507
20	96	44	94	5	94	96	51	4	29	96	609
21	41	69	97	25	7	55	48	32	8	5	387
22	18	46	47	83	6	85	45	93	16	72	511
23	15	98	74	90	15	98	71	60	59	94	674
24	45	17	51	51	2	7	94	2	4	3	276
25	49	19	92	79	8	94	80	5	82	10	518
26	83	47	16	49	16	92	78	4	13	18	416
27	48	50	14	92	17	94	14	18	7	7	361
28						NO DATA					
29	2	2	48	51	3	48	3	2	85	23	286
30						NO DATA					
31						NO DATA					
32						NO DATA					
33						NO DATA					
34						NO DATA					

PATIENT DEPENDENCE DATA COLLECTED BY CARERS WITHIN ONE WEEK OF ADMISSION: TIME A, n=27

APPENDIX 8.5

Patient Number	GETS ABOUT / CONFINED TO BED	NEVER CONFUSED / LOST	HELPFUL / DIFFICULT	CONVERSATION	FEEDING	DRESSING	SLEEPING	URINARY CONTINENCE	RESTLESS	MOOD	Visual Analogue Scale **TOTALS**
1	NO DATA										
2	42	89	84	85	37	81	89	93	75	75	750
3	96	49	51	78	52	94	39	80	14	13	566
4	83	84	76	80	81	72	67	98	90	90	821
5	95	74	73	74	13	95	73	94	74	51	716
6	95	49	25	25	50	75	80	10	53	15	477
7	39	77	39	71	8	95	50	96	76	13	564
8	DISCHARGED										
9	95	96	96	96	51	96	95	52	94	93	864
10	NO DATA										
11	NO DATA										
12	82	95	85	98	97	97	88	96	85	95	918
13	4	69	74	87	4	4	97	13	98	85	535
14	8	64	94	22	6	21	96	97	25	6	439
15	98	49	52	15	17	94	50	50	50	13	488
16	NO DATA										
17	97	91	94	96	33	95	91	86	22	92	797

PATIENT DEPENDENCE DATA COLLECTED BY CARERS
SIX WEEKS AFTER INTIAL ATTENDANCE: TIME B

Patient Number	GETS ABOUT / CONFINED TO BED	NEVER CONFUSED / LOST	HELPFUL / DIFFICULT	CONVERSATION	FEEDING	DRESSING	SLEEPING	URINARY CONTINENCE	RESTLESS	MOOD	Visual Analogue Scale TOTALS
18	44	75	5	71	7	94	75	12	87	7	477
19	48	48	73	79	50	95	12	94	79	52	630
20	NO DATA										
21	NO DATA										
22	DISCHARGED										
23	35	98	85	91	36	96	77	53	51	98	720
24	44	31	55	54	2	12	96	8	1	11	314
25	10	45	83	83	16	83	13	91	4	4	432
26	NO DATA										
27	87	96	51	90	50	95	19	94	13	52	647
28	NO DATA										
29	NO DATA										
30	DISCHARGED										
31	NO DATA										
32	DISCHARGED										
33	NO DATA										
34	DISCHARGED										

PATIENT DEPENDENCE DATA COLLECTED BY CARERS
SIX WEEKS AFTER INITAL ATTENDANCE: TIME B, n=18

APPENDIX 8.5

Patient Number	GETS ABOUT / CONFINED TO BED	NEVER CONFUSED / LOST	HELPFUL / DIFFICULT	CONVERSATION	FEEDING	DRESSING	SLEEPING	URINARY CONTINENCE	RESTLESS	MOOD	Visual Analogue Scale TOTALS
1						NO DATA					
2						NO DATA					
3	95	48	49	81	48	96	82	86	51	22	658
4	69	78	77	87	88	96	83	99	94	82	853
5	85	78	97	47	47	77	52	79	91	80	733
6	97	75	93	78	83	97	96	55	82	50	806
7	68	64	81	89	16	90	72	97	83	69	729
8						DISCHARGED					
9	96	85	95	97	82	96	95	95	94	93	928
10	84	15	54	5	13	90	94	5	11	12	383
11						DISCHARGED					
12	95	95	82	96	96	98	89	96	89	92	928
13						DISCHARGED					
14	30	66	41	9	6	28	70	53	9	8	320
15	97	29	27	28	4	98	35	37	6	23	384
16						DISCHARGED					
17						DISCHARGED					

PATIENT DEPENDENCE DATA COLLECTED BY CARERS
12 WEEKS AFTER INITIAL ATTENDANCE: TIME C

APPENDIX 8.5

Patient Number	GETS ABOUT/ CONFINED TO BED	NEVER CONFUSED/ LOST	HELPFUL/ DIFFICULT	CONVERSATION	FEEDING	DRESSING	SLEEPING	URINARY CONTINENCE	RESTLESS	MOOD	Visual Analogue Scale **TOTALS**
18	2	96	50	51	3	80	53	5	97	6	443
19	82	80	19	80	4	93	18	51	13	52	492
20	84	22	95	6	26	96	5	6	38	94	472
21						DISCHARGED					
22						DISCHARGED					
23	8	87	68	83	4	81	68	25	49	75	548
24						NO DATA					
25	12	13	87	77	14	86	79	93	52	6	519
26						NO DATA					
27	47	46	15	92	46	95	7	97	20	18	483
28						DISCHARGED					
29						DISCHARGED					
30						DISCHARGED					
31						NO DATA					
32						DISCHARGED					
33						NO DATA					
34						DISCHARGED					

PATIENT DEPENDENCE DATA COLLECTED BY CARERS
12 WEEKS AFTER INITIAL ATTENDANCE: TIME C, n=16

APPENDIX 8.5

Patient Number	GETS ABOUT / CONFINED TO BED	NEVER CONFUSED / LOST	HELPFUL / DIFFICULT	CONVERSATION	FEEDING	DRESSING	SLEEPING	URINARY CONTINENCE	RESTLESS	MOOD	Visual Analogue Scale TOTALS
1	87	71	53	83	44	91	74	92	53	72	720
2	DISCHARGED										
3	NO DATA										
4	12	93	89	6	95	96	79	98	97	88	753
5	97	49	51	16	1	94	51	83	6	48	496
6	DISCHARGED										
7	86	47	44	67	17	96	18	97	45	16	533
8	DISCHARGED										
9	97	98	96	96	90	97	95	52	89	96	906
10	69	22	45	2	78	94	51	2	8	9	380
11	DISCHARGED										
12	97	97	98	97	97	98	68	96	96	29	873
13	DISCHARGED										
14	DISCHARGED										
15	99	50	19	20	25	95	53	53	7	7	428
16	DISCHARGED										
17	DISCHARGED										

PATIENT DEPENDENCE DATA COLLECTED BY CARERS
SIX MONTHS AFTER INITIAL ATTENDANCE: TIME D

APPENDIX 8.5

Patient Number	GETS ABOUT/ CONFINED TO BED	NEVER CONFUSED/ LOST	HELPFUL/ DIFFICULT	CONVERSATION	FEEDING	DRESSING	SLEEPING	URINARY CONTINENCE	RESTLESS	MOOD	Visual Analogue Scale TOTALS
18	5	98	17	76	4	76	76	31	80	29	492
19						NO DATA					
20						DISCHARGED					
21						DISCHARGED					
22						DISCHARGED					
23	70	97	42	84	2	96	53	78	22	72	616
24						NO DATA					
25						DISCHARGED					
26						DISCHARGED					
27						NO DATA					
28						DISCHARGED					
29						DISCHARGED					
30						DISCHARGED					
31						DISCHARGED					
32						DISCHARGED					
33						NO DATA					
34						DISCHARGED					

PATIENT DEPENDENCE DATA COLLECTED BY CARERS
SIX MONTHS AFTER INITIAL ATTENDANCE: TIME D, n=10

PATIENT NUMBER	CARER RELATIONSHIP	NO. OF PEOPLE IN HOUSEHOLD	TYPE OF ACCOMMODATION
1	WIFE	2	FLAT
2	SISTER	2	SHARED HOUSE
3	WIFE	3	FLAT
4	WIFE	2	1ST FLOOR MAISONETTE (NO LIFT)
5	FRIEND (LONG TERM LODGER)	2	2 BEDROOMED HOUSE
6	DAUGHTER	3	HOUSE
7	WIFE	5	BEDSIT + 2 BEDSITS 1 HIS CHILDREN AND 1 A FRIEND
8	NO IMMEDIATE CARE, LIVED ALONE	1	
9	DAUGHTER	2	PATIENTS HOUSE - 3 BEDROOMS
10	HUSBAND	2	HOUSE
11	HUSBAND	2	FLAT
12	WIFE	2	FLAT
13	WIFE	2	HOUSE
14	WIFE	2	SMALL SHELTERED ACCOMMODATION FLAT
15	DAUGHTER	2	FLAT (NO LIFT)
16	WIFE	2	FLAT
17	WIFE	2	FLAT

CARER AND HOUSEHOLD RELATIONSHIPS

PATIENT NUMBER	CARER RELATIONSHIP	NO. OF PEOPLE IN HOUSEHOLD	TYPE OF ACCOMMODATION
18	DAUGHTER	3 SON-IN-LAW	HOUSE
19	HUSBAND	2	FLAT
20	DAUGHTER	5	HOUSE
21	SON	2	HOUSE
22	WIFE	2	FLAT
23	DAUGHTER	5 SON-IN-LAW AND 2 GRAND-DAUGHTERS	4 BEDROOMED HOUSE OWNED BY DAUGHTER
24	DAUGHTER	1	LIVES IN NEXT STREET TO DAUGHTER
25	WIFE	2	FLAT
26	WIFE	2	FLAT
27	WIFE	2	FLAT
28	HUSBAND	2	FLAT
29	WARDEN	--	WARDEN ASSISTED ACCOMMODATION
30	HUSBAND	2	HOUSE
31	HUSBAND	2	FLAT
32	HUSBAND	2	FLAT
33	HUSBAND	2	FLAT
34	WIFE	--	--

CARER AND HOUSEHOLD RELATIONSHIPS

APPENDIX 9.2

PATIENT NUMBER	COPING/UNABLE TO COPE	NOT ANXIOUS EXTREMELY ANXIOUS	VISUAL ANALOGUE SCALE TOTALS
1	51	74	125
2	86	90	176
3	48	73	121
4	42	40	82
5	76	77	153
6	49	88	137
7	49	77	126
8	NO CARER		
9	51	50	101
10	22	76	98
11	71	86	157
12	69	86	155
13	70	95	165
14	10	77	87
15	73	75	148
16	13	48	61
17	28	45	73
18	44	49	93
19	48	93	141
20	51	53	104
21	45	47	92
22	47	73	120
23	37	83	120
24	50	90	140
25	13	50	63
26	14	78	92
27	50	14	64
28	NO DATA		
29	WARDEN - INTERVIEWED		
30			
31			
32			
33			
34			

CARERS' SELF REPORTED ANXIETY ABOUT AND FELT ABILITY TO COPE WITH PATIENT WITHIN ONE WEEK OF ADMISSION: TIME A, n=26

PATIENT NUMBER	COPING/UNABLE TO COPE	NOT ANXIOUS EXTREMELY ANXIOUS	VISUAL ANALOGUE SCALE TOTALS	PATIENT NUMBER	COPING/UNABLE TO COPE	NOT ANXIOUS EXTREMELY ANXIOUS	VISUAL ANALOGUE SCALE TOTALS
1	NO DATA			18	50	76	126
2	59	78	137	19	13	93	106
3	48	51	99	20	NO DATA		
4	12	13	25	21	NO DATA		
5	52	86	138	22	DISCHARGED		
6	52	92	144	23	58	84	142
7	51	13	64	24	54	93	147
8	DISCHARGED			25	48	48	96
9	17	49	66	26	NO DATA		
10	NO DATA			27	50	82	132
11	NO DATA			28	NO DATA		
12	33	79	112	29	NO DATA		
13	98	97	195	30	DISCHARGED		
14	77	82	159	31	NO DATA		
15	49	51	100	32	DISCHARGED		
16	NO DATA			33	NO DATA		
17	69	96	165	34	DISCHARGED		

CARERS' SELF REPORTED ANXIETY ABOUT AND FELT ABILITY TO COPE WITH PATIENT SIX WEEKS AFTER INITIAL ATTENDANCE: TIME B, n=18

APPENDIX 9.2

PATIENT NUMBER	COPING/UNABLE TO COPE	NOT ANXIOUS EXTREMELY ANXIOUS	VISUAL ANALOGUE SCALE TOTALS
1	NO DATA		
2	NO DATA		
3	16	49	65
4	80	74	154
5	49	91	140
6	95	95	190
7	52	56	108
8	DISCHARGED		
9	73	19	92
10	15	64	79
11	DISCHARGED		
12	50	81	131
13	DISCHARGED		
14	15	56	71
15	34	34	68
16	DISCHARGED		
17	DISCHARGED		
18	69	93	162
19	16	79	95
20	29	49	78
21	DISCHARGED		
22	DISCHARGED		
23	32	80	112
24	NO DATA		
25	52	12	64
26	NO DATA		
27	19	79	98
28			
29			
30			
31			
32			
33			
34			

CARERS' SELF REPORTED ANXIETY ABOUT AND FELT ABILITY TO COPE WITH PATIENT TWELVE WEEKS AFTER INITIAL ATTENDANCE: TIME C, n=16

PATIENT NUMBER	COPING/UNABLE TO COPE	NOT ANXIOUS EXTREMELY ANXIOUS	VISUAL ANALOGUE SCALE TOTALS
1	50	54	104
2	DISCHARGED		
3	NO DATA		
4	87	89	176
5	80	94	174
6	DISCHARGED		
7	37	63	100
8	DISCHARGED		
9	51	48	99
10	3	16	19
11	DISCHARGED		
12	22	80	102
13	DISCHARGED		
14	DISCHARGED		
15	30	33	63
16	DISCHARGED		
17	DISCHARGED		

PATIENT NUMBER	COPING/UNABLE TO COPE	NOT ANXIOUS EXTREMELY ANXIOUS	VISUAL ANALOGUE SCALE TOTALS
18	51	94	145
19	NO DATA		
20	DISCHARGED		
21	DISCHARGED		
22	DISCHARGED		
23	51	88	139
24	NO DATA		
25	DISCHARGED		
26			
27			
28			
29			
30			
31			
32			
33			
34			

CARERS' SELF REPORTED ANXIETY ABOUT AND FELT ABILITY TO COPE WITH PATIENT SIX MONTHS AFTER INITIAL ATTENDANCE: TIME D, n=10

APPENDIX 9.3

	TIME A		TIME B	
PATIENT NUMBER	NURSE	CARER	NURSE	CARER
2	585	753	412	750
3	394	633	349	566
4	587	810	421	821
5	351	616	356	716
6	432	380	143	477
7	347	718	225	564
9	659	873	675	864
12	701	918	752	918
14	139	471	149	439
15	480	443	714	488
18	452	360	383	477
19	472	507	542	630
23	526	674	515	720
24	232	276	314	314
25	415	518	358	432
27	210	361	335	647

COMPARISON OF NURSE AND CARER RATINGS OF PATIENTS RATED AT BOTH TIME A AND TIME B n = 16

APPENDIX 9.3

	TIME A		TIME C	
PATIENT NUMBER	NURSE	CARER	NURSE	CARER
3	394	633	382	658
4	586	810	462	853
5	351	616	305	733
6	432	380	497	806
7	347	718	417	729
9	659	873	473	928
10	478	397	418	383
12	701	918	675	928
14	139	471	268	320
18	452	360	347	443
19	472	507	649	492
20	236	674	568	548
23	526	674	568	548
25	415	518	359	519
27	210	361	418	483

COMPARISON OF NURSE AND CARER RATINGS OF PATIENTS RATED AT BOTH TIME A AND TIME C n=15

APPENDIX 9.3

	TIME A		TIME D	
PATIENT NUMBER	**NURSE**	**CARER**	**NURSE**	**CARER**
1	615	450	386	720
4	587	810	613	753
5	351	616	311	496
7	347	718	503	533
9	659	873	524	906
10	478	397	364	380
12	701	918	733	873
15	480	443	265	428
18	452	360	287	492

COMPARISON OF NURSE AND CARER RATINGS OF PATIENTS RATED AT BOTH TIME A AND TIME D n=9