

TOWARDS IMPROVING QUALITY OF LIFE FOR THE  
DEPENDENT ELDERLY AND THEIR CARERS

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THIS THESIS WAS COMPOSED BY MYSELF AND ALL WORK WAS UNDERTAKEN BY  
MYSELF EXCEPT WHERE EXPLICITLY STATED IN THE TEXT.

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**ABSTRACT**

Literature review reveals that there are deficiencies in long-term care services for the elderly in the United Kingdom. Patterns of care are changing rapidly with substantial growth in private institutional care and increasing recognition of the impact of dementia for carer burden and service provision. Central government proposals for reform promote an increased role for consumers of services. In spite of general consensus that the goals of long-term care are to improve quality of life, there has been little research into quality of life evaluation.

The aims of this thesis were to describe views of the dependent elderly and their carers about long-term care services, and to explore ways in which a more consumer-oriented approach to the delivery of services might influence the outcomes of care.

Studies were designed as paradigms and populations were small. Consumer perceptions of services were described for 17 carers of the demented elderly in primary care, 47 carers of patients admitted to a geriatric assessment unit, 47 patients attending a geriatric day hospital and 28 patients in long-term geriatric hospital care. A retrospective study was undertaken of the correlates of quality of life gains for carers following long-term institutionalization of 68 patients. A methodology was developed for evaluation of quality of life in private nursing homes and long-term hospital care. This was used to compare 3 private nursing homes, 12 long-term care geriatric and 10 psychogeriatric wards which serve a Scottish City. The use of consumer-oriented audit was explored for setting standards in long-term geriatric hospital care, and for improving primary care support to carers of the demented elderly.

Taking the results of the studies together, the following conclusions were reached:

- (1) Consumers lack information about long-term care services
- (2) Perceived unmet needs for services are modest, but specific
- (3) Evaluation of long term care services from a consumer perspective is possible using a variety of approaches
- (4) There is considerable scope to change practice towards improving quality of life of the dependent elderly and their carers
- (5) There is no evidence that a consumer-oriented approach leads to unmanageable demand for resources, at least in the short term.

Incidental findings included:

- (1) A primary care team's support to the carers of the demented elderly was inadequate not because of failure to identify cases, but by failure to support known cases
- (2) The level of community support or its perceived adequacy by carers did not affect the likelihood of institutionalization of elderly patients following admission to acute hospital care. However, carers were accurate in their predictions of that outcome, and carers quality of life improved most for those who had greatest proximity to dependents.
- (3) There was a large overlap of dependency between geriatric and psychogeriatric patients in long-term hospital care suggesting an illogical administrative structure

- (4) There was lower patient dependency, cost of care (to the taxpayer) and higher nurse morale in nursing homes than in long-term hospital wards, but quality of life appeared to depend on factors operating at the level of the individual homes or wards, rather than which sector provided care.

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## INTRODUCTION

"Grow old along with me  
The best is yet to be  
The last of life for which the first was made"<sup>1</sup>

Health and social services in the United Kingdom which provide long-term care for the elderly in domiciliary and institutional settings will be radically changed if two Government Command Bills (Secretaries of State for Health, Social Security, Wales and Scotland, 1989; Secretaries of State for Health, Wales, Northern Ireland and Scotland, 1989) become law.

Both Bills recommend increased attention to the protection of the interests of the users of services. Users are referred to as "consumers" in this context and protection of their interests as "consumerism".

A shift of emphasis towards consumerism in long-term care may have profound effects for both professionals and consumers, because a consumer-oriented philosophy might challenge professional-dominated assessment of need and allocation of resources which has been the underlying philosophy of health care delivery in the United Kingdom since the early days of the National Health Service (Cooper, 1975). In spite of the advocacy of consumerism little is known about how consumers view services, how to measure consumer opinion, or the resource implications of an increased role for consumers in service planning and provision.

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<sup>1</sup>Robert Browning (1812-1889)  
Quotation from "Rabbi ben Ezra".

These are important issues which need to be addressed for there to be a shift towards consumerism in long-term care and if its effects are to be measured.

At present Health and Social Services in the United Kingdom which provide long-term care for the elderly include geriatric and psychogeriatric hospital services (including day hospitals and long-term care wards), primary care services (where general practitioners often lead a primary care team which includes district nurses and other workers), non-NHS institutional care services (private, voluntary and local authority homes), domiciliary services (such as the home help service) run by local authority social work departments, and private and voluntary domiciliary services (such as the crossroads care attendant scheme). In addition, the provision of specialist housing (such as sheltered housing) and financial support from social security are important components of the long-term care system.

In spite of this impressive array of services, most long-term care for the elderly is provided by family members and other informal supporters rather than by formal services (Jones and Vetter, 1985). For this reason, the views and role of carers are important in a discussion of long-term care from a consumer perspective. There has been a considerable amount of research which has documented the needs of carers for information and services (Morris et al, 1988) but there has been remarkably little documentation of effective strategies to relieve carer burden or meet their needs.

There is also little information even at a basic level about consumer perceptions of services, including their knowledge of services, satisfaction with them and perceived need for them. Simple descriptive research to measure these factors in different long-term care settings would provide useful information about how consumers perceive long-term care services, and could suggest possibilities for operational research to improve service

provision in line with consumer perceptions.

The quality of life of consumers, particularly those in institutional care, is widely regarded as a vital goal of service provision for the elderly (British Geriatrics Society-Royal College of Nursing, 1975; World Health Organisation, 1986). Though quality of life is difficult to measure and hard to define (Woods, 1987), recent developments in quality evaluation (e.g., Peace et al, 1979) will facilitate institutional care research based on quality of life measures.

At this stage, given the lack of basic information about quality of life in institutional care settings, simple descriptive or comparative research in different care settings is needed, including documentation of the views and preferences of patients. Such information would be valuable for discussion about who should provide long-term institutional care for the elderly (Impallomeni & Nicholl, 1990) and could also suggest strategies for improvement of care in line with consumer preferences.

This thesis concentrates on two main themes:

- 1) Description of consumer perceptions of long-term care services
- 2) Evaluation of quality of life in long-term institutional care.

It is beyond the scope of the thesis to present data which could be generalised to a national scale, or to evaluate all long-term care services from a consumer perspective.

A study of meeting the needs of the carers of the demented elderly in primary care was undertaken because of a unique opportunity to evaluate the needs of a well-defined population of carers, and because dementia is widely perceived to be a major public health problem (Scottish Home and Health Department, 1980a; Wilcock, 1988; Hay & Ernst, 1987) with a great impact on carers (Morris et al, 1988).

Further studies of perceptions of long-term care services of different consumer groups were undertaken in a geriatric day hospital, a geriatric assessment ward and in long-term care geriatric wards. The variety of settings and populations allows more general conclusions to be drawn about consumer perceptions of long-term care services.

Evaluation of quality of life in institutional care was undertaken in all the private nursing homes and long-term care wards of the Departments of Geriatric and Psychogeriatric Medicine in a Scottish city, the first study of its kind in the United Kingdom.

All these studies provide meaningful information about long-term care services from a consumer perspective within a limited context, defined by their geographic locations. It is hoped that the studies will provide the basis for large-scale research to address the generality of findings, as well as suggesting some means for improving the quality of life of the dependent elderly and their carers.

## LITERATURE REVIEW

### 1. Introduction

In order to review the literature of long-term care services for the elderly from a consumer perspective, it is necessary to cut across several disciplines. These include the sciences of psychology, sociology, health care economics and epidemiology; the fields of health, social policy and administration; and the practice of geriatric medicine, psychiatry, general practice and social work. Although there is some overlap there is inadequate cross-reference between the different disciplines. In addition, there are differences of approach. An example of this is that the medical sciences rely heavily on hypothesis-testing and quantitative data analysis whereas the social sciences rely more on descriptive methodology and qualitative data analysis. This means that the task of drawing together the literature from the different disciplines is difficult but is probably all the more important for being so.

Discussion of much of the Scandinavian literature about long-term care services for the elderly has been avoided due to difficulties of access and language barriers. It has to be admitted, therefore, that some important and relevant material about advanced models of long-term care which apply in some Scandinavian countries has been omitted.

On the other hand, many American references are included. Although American culture and systems of care are very different from the United Kingdom, there have been important developments in the United States which predate current trends in the United Kingdom. These include the rise of consumerism, an interest in quality regulation in long-term care, especially of private nursing homes, and a major investment in research into carer burden. If carefully evaluated there may be useful lessons for the United Kingdom from the American literature.

## 2. Demographic Trends

It is customary to start discussion of services for the elderly with reference to demographic trends.

Although there may be a deceleration in the increase in the population aged greater than 65 in the UK, the population aged greater than 80 is likely to increase substantially in the next few decades (Warnes, 1989; MacLennan 1988b). It is this group, the very old, who have the highest prevalence of dependency (Office of Population Censuses and Surveys, 1988; Bond & Carstairs, 1982).

There is an argument as to whether advances in medicine will lead to a compression of dependency prior to death (Fries, 1980) or to the survivorship of patients with increased dependency from problems which would have been fatal in the past, the so-called "survival of the unfittest" (Isaacs, 1972). A recent study found that the gain in life expectancy of the elderly between 1976 and 1985 was not at the expense of any substantial increase in time spent in hospital in the final year of life (Henderson et al., 1990). Although debate about the contribution of modern medicine to dependency in old age tends to have been polarised to these two opposing effects, the weight of evidence suggests that a dependent elderly population will remain for the foreseeable future in spite of advances in medicine (Guralnik & Schneider, 1987), and consequently the need to provide long-term care services for the elderly will also remain.

## 3. Community Care

### 3.1. Problems and Developments

In 1981 in Scotland only 1.7% of the elderly population were in permanent residential care, 2.1% in long-term hospital care and a smaller proportion in nursing homes (Age Concern Scotland, 1989). Most long-term



care is provided in the community. Even for the elderly who have severe problems, such as dementia, only a minority are in institutional care (Lindesay et al, 1989).

Central government response to meeting the care needs of the dependent elderly gives priority to care in the community (Department of Health and Social Security, 1981). However, community care in the United Kingdom is widely perceived to have been ineffective (Barber & Haynes, 1988; Grundy, 1987; Anderson, 1987; Richards, 1987; Murphy, 1987).

The report of the Audit Commission for Local Authorities in England and Wales (Audit Commission, 1986) was perhaps most influential in clarifying the failures of community care policy. Problems identified included difficulty shifting funds between health and social services; difficulty integrating health and social policy at local level; perverse financial incentives to shift care between different agencies; and poor staff training.

Central government response to the Audit Commission report led to the publication of the Griffiths Report on Community Care (Griffiths, 1988), followed after some delay by a White Paper (Secretaries of State for Health, Social Security, Wales and Scotland, 1989) whose proposals include the designation of local authorities as the lead agency for the financing, planning and purchase of long-term care services in institutions or community. Packaged individual care plans are envisaged based on experience of a large and well-designed experiment in Kent where fiscal and advocacy responsibility for social support to the frail elderly was delegated to key workers at a local level. The intervention group showed reduced mortality, hospital use and institutionalisation of dependents, as well as increased consumer satisfaction with services (Davis & Challis, 1986a, 1986b).

American experiments with similar systems have shown less benefit. Although decentralised systems of health care delivery to the elderly were shown to promote increased voluntary and community support, they were also less efficient (Alter, 1988).

An example is that a 27-centre study of demonstration project case-management systems designed to determine whether case-management systems would control costs by reducing institutionlisation (Weissart, 1988). The studies failed to show this effect (Wooldridge & Shore, 1988; Garber, 1988) although there were some positive subjective benefits reported by carers in some centres (Garber, 1988). Kane (1988) suggests that these largely negative results might be reversed if the demonstration projects were continued in the long-term.

The success of case-management systems may depend on how they are deployed at a local level (Murphy, 1989). There may be conflict between case-managers and other professionals, and tension between advocacy and rationing of services (Hunter, 1987). As American experience has shown, the success of case-management systems is not guaranteed, and there will therefore be a need to evaluate case-management systems at a local level as they are developed in the United Kingdom (Ashley-Miller, 1990).

In parallel with proposals for reform of community care services, a new contract for general practitioners has been formulated. This requires general practitioners to undertake annual checks on those in their practices aged greater than 75 years (Chisholm, 1990).

Early descriptive studies in elderly populations revealed a high prevalence of disabilities not previously known to professionals (Anderson & Cowan, 1955; Akhtar et al, 1973; Williamson et al, 1964), but more recent ones described lower levels of ill-health in the elderly not in contact with primary care teams (Ebrahaim et al, 1984; Stuart, 1984; Williams, 1984; Williams & Barley, 1985) and general practitioners appear to be well-placed

to employ consultation-based screening (Freer, 1987; Gray, 1987). Screening is perceived by general practitioners to be of low importance (Jachuck & Mulcahy, 1987) and is likely to generate considerable workload (Rowarth, 1989).

Two controlled trials of geriatric screening and surveillance in primary care, one in the UK and the other in Denmark, report some benefits with increased satisfaction with services (Tulloch & Moore, 1979) and decreased hospital admission and mortality (Hendriksen et al, 1984, 1989) in the intervention groups.

Many different schemes for screening, and surveillance, have been described (Taylor et al, 1983; Taylor & Buckley, 1987).

Local variability in practice will mean that small-scale studies will be required to evaluate the benefits of different approaches to screening the elderly in primary care.

### 3.2. Carer Burden

Central government policy for community care of the dependent elderly promotes care by the community, that is by relatives, friends and neighbours, with only a limited role for service provision (Department of Health and Social Security, 1981).

There is no evidence that families today are less caring for their elderly dependents than they were in the past, in spite of a long-held myth about a golden-age of family care (Evans & Williamson, 1988). On the whole, families today are willing to make sacrifices in order to care for their elderly dependents (Brody, 1977, 1981; Brody et al, 1978, 1984; Isaacs, 1971).

Characteristically, most care is provided by the spouse or daughter of the dependent and female carers outnumber males by a factor of 3:1 (Jones et al, 1983; Equal Opportunities Commission, 1980; Luker & Perkins, 1987).

Carers appear to receive little in the way of support from formal services (Jones, 1986; Jones & Vetter, 1984). Indeed, the presence of a carer may prevent problems in the dependent coming to the attention of their general practitioner (Luker & Perkins, 1987).

Burden on carers can be considerable, be it through curtailment of social life (Jones & Vetter, 1984; Moritz et al, 1989), psychological disturbance (Sanford, 1975), impaired physical health (Pruchno & Potashnik, 1989), or financial loss by restriction of employment (Hay & Ernst, 1987).

Although adult children of elderly dependents appear to be willing to make these sacrifices, it could be asked at what point does caregiving become intolerable because of the burden imposed on carers?

Carer burden may be a complex phenomenon which encompasses general psychological upset, mood change and changes in social functioning (Livingston, 1987), as well as the subjective interpretations of carers about burden in their caregiving role (Poulshock & Deimling, 1984). On the other hand, simple measures of psychological upset such as the scaled version of the General Health Questionnaire (Goldberg & Hillier, 1979) are useful research tools as they are easy to apply and results can be compared with established population norms (Goldberg, 1972).

The availability and amount of family support appears to be an important factor which reduces the risk of institutionalisation (Palmore, 1976; Branch & Jaffe, 1982; McLennan et al, 1984; Bergmann, 1985). Increased carer burden may increase the chances of institutionalisation (Colerick & George, 1986; Zarit et al, 1986; George & Gwyther, 1986), though Gilhooly (1986) found no association between carer well-being and desire to institutionalise demented dependents. Differences in community care service provision in the United States have been correlated with risk for institutionalisation (Cohen et al, 1988; Nardone, 1980), but the interaction

between carer burden, community care service provision and risk for institutionalisation has not been well documented in the United Kingdom and further research is required (Scottish Home and Health Department, 1987).

As well as trying to evaluate the importance of carer burden as a predictor of institutionalisation one could also ask whether institutionalisation of dependents reduces carer burden. Levin et al (1983) found that institutionalisation of confused elderly dependents was strongly associated with reduction in carer burden. However, Chenoweth and Spencer (1986) argue that institutionalisation of a dependent produces unique stresses for carers. Colerick and George (1986) found an increase in psychotropic drug use in carers following institutionalisation of dependents, and Jones (1986) found increased stress in a small group of carers whose elderly dependents had been institutionalised. It appears that institutionalisation of a dependent may carry its own stresses for carers which according to Hansen et al (1988) could be reduced if carers were involved in the process of care following institutionalisation of their dependents.

### 3.3. The Impact of Dementia

Community care for the demented elderly is an especially important area of concern and is the top priority for service development in Scotland (Scottish Home and Health Department, 1988).

There is widespread recognition of the large and costly public health impact of dementia (Scottish Home and Health Department, 1980a; Wilcock, 1988; Hay & Ernst, 1987; Anonymous, 1987; Huang et al, 1985). However, diagnostic difficulties pose problems for accurate estimation of its prevalence. The oft-quoted prevalence rates of around 1 in 10 aged over 65 and 1 in 5 aged over 80 (e.g. Health Advisory Service, 1982) are based on extrapolations of early research where estimates for prevalence in the older

groups in particular were based on small numbers with wide confidence limits (Kay et al, 1964, 1970).

Recent reviews would suggest a scaling down of prevalence rates for dementia to 1 in 100 aged 65-75 and 1 in 10 aged more than 75 (Henderson, 1986; Ineichen, 1987). The magnitude of the problem in the community may be even lower according to recent studies (Lindesay et al, 1989; Clarke et al, 1984, 1986), although these studies may have used insensitive screening instruments to identify cases, and follow-up may reveal a higher proportion of cases with probable or definite dementia (Kay et al., 1990). The apparent reduction in the prevalence of dementia could be due to a true decline in the incidence of dementia (Hagnell et al, 1981). Alternatively, low prevalence rates may reflect a shift of demented subjects from community to institutional care in recent years. A high institutionalisation rate for moderate or severe dementia has been found recently (Levin et al, 1983; Knopman et al, 1988) and changing patterns of mental illness in hospital suggest increased use of hospital beds by demented patients (Christie, 1982; Bond, 1987; Sulkava et al, 1983).

Dementia in the dependent appears to be a major risk factor for institutionalisation (Branch & Jeffe, 1982; MacLennan et al, 1984) and has a greater impact on carers than caring for other groups such as the physically impaired (Grad & Sainsbury, 1968; Poulshock & Deimling, 1984) or the mentally handicapped (Whittick, 1988).

It is generally agreed that behavioural disturbance is less well-tolerated by carers than physical disability (Sanford, 1975; Gilleard et al, 1984a, 1984b; Argyle et al, 1984; Green et al, 1982; Rabins et al, 1982; Morris et al, 1988; McCulloch, 1989). The impact of dementia varies at different stages of disease progression (Gilhooly, 1984; Johnson & Catalona, 1983; Chenoweth & Spencer, 1986) and according to the nature of the

behavioural disturbance. For example, apathetic behaviour was found to be associated with personal distress in carers, whereas mood disturbance was associated with negative feelings towards the dependent (Greene et al, 1982). A recent study reported that stress in co-resident carers of the demented elderly was not significantly higher than in matched controls (Eagles et al, 1987), but the demented subjects in this study may not have exhibited behavioural disturbance and a half had only mild cognitive impairment.

The carer-dependent relationship and carer characteristics are also important factors for carer burden. Female carers are more likely to suffer distress than males (Fitting et al, 1986) perhaps because females are more likely to provide a "hands-on" role (Horowitz, 1985). Sons are likely to become carers only in the absence of an available female sibling (Horowitz, 1985). The availability of other family support has been found to be associated with a lower burden (Zarit et al, 1980) and increased coping effectiveness (Scott et al, 1986). A commitment to caregiving on the basis of a good premorbid relationship has also been correlated with lower stress (Gilleard et al, 1984a; Horowitz & Shindelman, 1983) but a close bond has also been correlated with increased stress (Cantor, 1983). This paradox may be explained by differences in coping behaviour in different carer groups (Pagel et al, 1985; Whittick, 1987). It is clear that carers are a heterogenous group.

#### 3.4. Support for Carers

In spite of mounting evidence about the impact of dementia on carers, there is a lack of research activity to evaluate methods of supporting carers (Scottish Action on Dementia, 1986; Morris et al, 1988).

The view is held that it is the general practitioner who is responsible for case-finding (Arie, 1973, 1986), gatekeeping to resources (Royal College of Physicians, 1981) and advocacy for carers (Norman, 1987a). However, there is evidence that general practitioners are poorly suited for these roles by inclination (McAlpine & Martin, 1988), lack of training (Jacques & Burley, 1987), or lack of involvement in planning (McVeigh, 1988). There is great variability in general practice care of the elderly (Williams & Wilkin, 1988), and the proportion of elderly patients in a practice appears to have little relationship to workload (Wilkin & Williams, 1986). Furthermore, doubts have been cast on the ability of the primary care team to cooperate and coordinate their work for the elderly (Department of Health and Social Security, 1981) and there is little evidence of effectiveness or accountability in general practitioner care for the elderly (Day & Klein, 1986).

Evidence of effectiveness of other sources of support for carers also appears thin.

Gilleard et al (1984a), Levin et al (1983) and Gilhooly (1984) found little correlation between the level of community service support to carers and carer morale.

Of hospital services, those which provide respite for carers appear to be most valued (Scott et al, 1986; Sanford, 1988) and may help reduce carer burden (Cantor, 1983; Gilleard et al, 1984c; Winogrand et al, 1987).

Other developments in psychiatric services which might help reduce carer burden include the "quadruple support" system of a community dementia team, a domiciliary support service, day centres and carers support group (Lodge & McReynolds, 1987), a community-oriented psychiatric unit (Ebmeier et al, 1988) and a clinical psychology service for the elderly (Trepka & Whittick, 1987), but there is marked geographical variation in the provision of psychiatric services for the elderly in the UK (Wattis, 1988).



Counselling carers has been advocated (Sheldon, 1982; Arie, 1986). Information booklets for carers are available (Toner, 1985) and formal counselling programmes have been described (Pinkston et al, 1988; Lovett & Gallagher, 1988). Carers who perceive that they are well supported appear to be at less risk of adverse events (Zuckerman et al, 1984; Morycz, 1985), and carer support and education programmes have been reported to improve coping (Chiverton & Caine, 1989), decrease psychological morbidity (Brodaty & Gresham, 1989) and even reduce institutionalisation (Green et al, 1982).

### 3.5. Summary

Review of opinion and research of community care in the United Kingdom suggests that there are deficiencies in the delivery of services to the elderly. Much community care is provided by informal carers. Burden on carers may be considerable, especially for those who care for the demented elderly. Evidence about the effectiveness of services in relieving carer burden is sparse, although counselling of carers may be important. Central government proposals for reform include local authority-led case management for the elderly and annual review of elderly patients in primary care. Reforms are intended to promote a more consumer-oriented approach to care. There will be much scope for local innovation and variation in practice, and for research to evaluate the effectiveness of new systems of care.

## 4. Institutional Care

### 4.1. Historical Legacy and Current Developments

Goffman (1961) described the "total institution" characterised by no separation of work, leisure and family; block treatment and strict routine designed to fulfill the official aims of the institution and the importance of staff attitudes in shaping regime.

Most observers have found these characteristics in residential care for the elderly in the United Kingdom (Sinclair, 1988). Townsend (1962) in an influential study found that residential homes failed to meet the physical, psychological and social needs of residents, with loss of privacy and control and bad staff attitudes. Clough (1981) found a lack of choice and privacy for residents in old age homes. He was especially critical of the lack of positive choice on entry to homes. Booth (1985) maintained that the characteristics of the total institution described by Goffman, persist in old age homes of the 1980s, albeit with different regimens. Local authority residential homes have received much public criticism for a perceived failure to provide a high quality of life for residents. A negative image of residential care in the United Kingdom may be due to its origins in the poor law workhouse (Lewis & Wattis, 1988).

Private care establishments have also attracted criticism (National Union of Public Employees, 1986) but little research about quality of life in institutional care has been undertaken in the private sector or, indeed, in National Health Service long-term care hospital wards.

There also appears to be a lack of central planning for provision of institutional care for the elderly. Supplementary benefit for low income groups in private establishments has encouraged the trend towards a growth in this sector (Laing, 1988) but there is marked regional variation in the proportion of long-term care residents in private residential (Laing, 1985) and nursing home care (Irvine, 1987), a fact which was of great concern to the Audit Commission (1986). Concern has also been expressed about the escalating costs of private care subsidised through taxation (Primrose, 1988). There is evidence of patients living in private nursing homes who are independent in self-care, including some who are in receipt of supplementary benefit (Primrose & Capewell, 1986). There is however considerable overlap

in dependency of patients in residential homes and long-term geriatric care wards (Hodkinson et al, 1988; Wilkin, 1984). A proportion of up to about 30% of residents with moderate to severe confusion appears to be acceptable to other residents and staff in residential care (Wilkin et al, 1982), but the proportion of confused residents is higher in many residential homes and higher still in other institutional care settings (Norman, 1987b; Charlesworth & Wilkin, 1982; Christie, 1982; Bond et al, 1989a).

A contentious issue in institutional care for the elderly is whether to segregate or integrate demented from non-demented residents. Meacher (1972) in a classic study of institutional life, found evidence of patients dumped in institutional care who were labelled as demented without adequate assessment. They were often heavily sedated and physically restrained, literally "taken for a ride". He argued against segregated homes for the demented on these grounds. On the other hand, Norman (1987b) in a well-argued discussion based on thorough examination of current institutional care practice for the severely demented was firmly in favour of segregated care for the severely demented in order to attend to their special needs.

The system for financing long-term care is thought to be the major factor in inappropriate placement (Maynard & Smith, 1983). Concerns about escalating costs and the need to allocate care on the basis of dependency have prompted calls for preadmission assessment of target groups prior to entry to private institutions (MacLennan, 1988a; Age Concern Scotland, 1987; British Geriatrics Society, 1987). There is research evidence which supports the value of a medical assessment of elderly persons prior to a move to residential care (Rafferty et al, 1987). The legacy of Warren (1946) who demonstrated the rehabilitation potential of the chronic aged sick in institutional care has encouraged the view that a geriatrician should be responsible for elderly subjects in all long-term care institutions so that

opportunities for rehabilitation are not missed (Millard et al, 1989), but following community care reforms, local authorities are to be given the lead role for the purchase of care and its regulation although not necessarily of its provision (Secretaries of State for Health, Social Security, Wales and Scotland, 1989). Further growth of private and voluntary sector care is likely.

#### 4.2 Private vs Public.

There is concern that private nursing homes should have comparable standards of care with National Health Service long-term care wards (British Geriatrics Society Scottish Branch, 1986). However, there is a lack of research which compares care in National Health Service long-term care wards with that in private nursing homes.

Private nursing homes have been criticised for drug-prescribing policies (Nolan & O'Malley, 1989) and inadequate medical review (Hepple et al, 1989), but so have National Health Service facilities (Fottrell & Sheikh, 1976; Ballinger, 1979). Private nursing homes may be more personalised and democratic than long-term geriatric hospitals (Wade et al, 1983), but there are differences in operational policy within either sector (Miller, 1985) which may be more important for outcomes of care than differences between sectors.

#### 4.3 Medical vs social models

Quality of care and quality of life of patients are both important in long-term institutional care (Denham, 1989) but they need to be distinguished. Davies (1983) argues that quality of care refers to processes, predominantly those of nursing and medical care, whereas quality of life is related more closely to social factors. A social rather than a medical model of care may

be more appropriate if quality of life of patients is the main goal in long-term care (Bond & Bond, 1987; Evers, 1981; Godber, 1987; Evans, 1989). However, Kane and Kane (1989) argue that a medical approach towards achieving high quality of care and a social approach towards achieving a high quality of life are not antithetical.

#### 4.4 Quality of life

It is recommended that quality of life should be maximised in care for the elderly (World Health Organisation, 1986; British Geriatrics Society and Royal College of Nursing, 1975) but quality of life is an ambiguous and complex phenomenon (Pearlman & Johnson, 1985; Pearlman & Uhlmann, 1988) which is difficult to measure and hard to define (Woods, 1987). Recent attention has been given to the development of a method for valid measurement of quality of life in health care settings - the Quality-adjusted life year (QALY) (Guyatt et al, 1986) where quality of life is weighted by consensus for different life situations and disease states according to implications for disability and distress. An intervention can be evaluated by its effects on life expectancy adjusted for quality of life. The efficiency of an intervention can be calculated by the cost incurred for each QALY so as to facilitate decision-making and the determination of priorities (Williams, 1985, 1987).

However, the QALY approach is limited by assumptions of validity which have yet to be proven or shown to apply to many real life health care dilemmas (Klein, 1989; Carr-Hill, 1989). In particular, the QALY as presently constructed does not appear to have sufficient sensitivity for use in long-term care for the elderly and discriminates, by definition, against patients with chronic disorder (Donaldson et al, 1988).

An approach towards a more precise understanding of quality of life in institutional care has been the development of the concept of "environmental-fit" (Davies & Knapp, 1981; Moos & Lemke, 1980; Kahana et al, 1980; Bland & Bland, 1983; Lemke & Moos, 1989) where quality of life is determined by the interaction between the characteristics of residents and their environment. Environment is taken to include the regime of the institution as well as its physical structure. The attitude and behaviour of care providers is a component of the environment of care (Hughes & Wilkin, 1978; Harris et al, 1977).

Coleman (1984) has used measurement of self-esteem for monitoring quality of life of the elderly and has shown how institutionalisation has variable effects on the elderly according to their sources of self-esteem. Peace et al (1979) developed an instrument for evaluation of quality of life of old people in residential care which includes measures of resident characteristics, features of the physical and social environment, staff morale and resident' perceptions of well-being. This instrument was applied in a major study of the residential life of old people (Willcocks et al, 1982) and it was suggested that an adapted version could be used in other sectors providing long-term institutional care for the elderly (Willcocks et al, 1987).

Perceived life satisfaction of residents is also suggested as useful for evaluation of quality of life (Kane et al, 1985). Instruments for measuring life satisfaction are available, including a British version (Luker, 1979) of a widely-used American instrument (Neugarten et al, 1961).

Ebrahim (1987) constructed a checklist of requirements for design and selection of instruments for valid measurement of quality of life. Factors to be taken into consideration include: consensus that the instrument measures that which it purports to; sensitivity to change; appropriateness for the population under study; test-retest reliability; inter-rater reliability; and ease of application. Ebrahim suggests that no single instrument for quality of life

measurement meets all these criteria for all populations. Furthermore, Kane and Kane (1981) suggest although scales can inform they cannot define quality of life.

In spite of practical difficulties for valid measurement of quality of life in institutional care there appears to be remarkable consensus about how institutions should try to promote quality of life of residents.

- a. Central government policy supports the promotion of individuality, dignity and expression of personal preference (Department of Health and Social Security, 1981).
- b. The influential Wagner Report on residential care (National Institute for Social Work, 1988) advocates much more choice for residents.
- c. The Centre for Policy on Ageing (1984) produced a code of practice for residential care which promotes privacy, autonomy, individuality, esteem, choice and responsible risk-taking.
- d. Horrocks (1986) suggests the need for choice, privacy and an individual care plan.
- e. Wilkin et al (1985) state that although the problems of institutional environments are well-documented, the lessons have not been implemented: these are to set and implement standards which preserve autonomy, dignity, privacy and respect.
- f. Marshall (1988) outlines principles of management which include valuing the rights, needs and individuality of residents in institutional care.
- g. In a major policy review of quality of care in American nursing homes, the Institute of Medicine (1986) argues for more attention to resident outcomes, especially civil rights.

Intervention studies in nursing homes in the USA have shown greatest benefit where individuality and resident preferences are respected, for example, by integrating elderly residents with their preferred friends and

family in the community (Harel & Noekler, 1982; Retsinas & Garrity, 1985) or where residents are given increased control and choice over home life (Mercer & Kane, 1979; Schulz, 1976; Langer & Rodin, 1976). In comparison a survey of 100 studies of programmes with therapeutic interventions in nursing homes showed little benefit (Bennett, 1983). In a thorough critique of research, policy and practice in nursing homes in the United States, Kane and Kane (1987) conclude that choice and control are important as well as the preservation of dignity, individuality and respect for preferences of residents.

In contrast to experience in the USA, there have been few attempts in the UK to evaluate interventions intended to improve quality of life of the elderly in institutional care or to compare different forms of care (Bland & Bland, 1983). An exception is the recently reported study of experimental nursing home care compared with conventional long-term geriatric hospital care (Bond et al, 1989b, c, d, e).

#### 4.5 Summary

Residential care for the elderly has appeared to be of poor quality to observers for many years. Recent attention has focussed on where institutional care should be provided. There is overlap of dependency in residential care, long-term hospital care and private nursing home care. Expansion of private care has occurred and is likely to escalate. Little is known about quality of care and quality of life of patients in hospital or nursing home care, but there is consensus about the goals of care; these are to promote choice, privacy, autonomy and respect for patients.

Recent developments in methodology provide opportunities to research these factors in institutional care.



## 5. The Consumer Viewpoint

### 5.1 Consumer perceptions

Horrocks (1985) classifies consumer perceptions of services for the elderly into 3 areas:

- 1) Satisfaction with services
- 2) Awareness of services
- 3) Involvement in planning and provision of services

He argues that these factors are powerful indicators of effectiveness of services.

There appears to be a growing trend towards the measurement of consumer satisfaction with services in the United Kingdom (Locker & Dunt 1978; Lebow, 1982; Anderson, 1989; Keeble & Keeble, 1989) although there have as yet been few studies in elderly populations.

In a survey of 251 elderly subjects living at home, Salvage (1986) found high levels of satisfaction with community services although there were some paradoxes in that some subjects had specific complaints about services for which they expressed high satisfaction. Luker (1981) found that elderly women were very satisfied with health visitor visits, but it was the social aspects of visiting which were perceived to be the most beneficial rather than effects on health.

Little is known about residents' perceptions of care in institutions in the United Kingdom (Wilkin & Hughes, 1987). A large study with 400 nursing home residents in 10 centres in the United States found that residents valued privacy, choice, courtesy, staff competence, and good quality food (Spalding, 1985). In another study from the United States (Kayser-Jones, 1986) where 50 nursing home residents were interviewed, it was found that 88% preferred

open-ward accommodation to single rooms, a surprising finding if privacy is important.

There appear to be some widely-held general opinions about services for the elderly. Salvage et al (1988), McAlpine & Wright (1982) and Kennedy and Acland (1976) all found that the elderly had a negative view of geriatric hospitals. Old people have been found to dislike charity and desire privacy (Age Concern, 1974). They want to remain independent, even of family support (Thomas, 1988) and prefer community to institutional care (Salvage, 1986; Wilkinson & Pelosi, 1987). There is general public support for community-based policies with institutional care reserved for those with mental impairment (West et al, 1984). Sheltered housing also appears to have widespread public appeal (Thompson & West, 1984) perhaps because a home-like environment and a measure of independence is maintained but is combined with the security of there being a warden to deal with emergencies.

There are reports that elderly dependents and carers value information about services (Sanford, 1988; Glosser & Wexler, 1985; Cornwell, 1989). However, consumer knowledge of services appears to be poor. Ritchie et al (1981) in a community survey found that 83% of elderly subjects did not know what a health visitor did, and 1 in 3 did not know what a district nurse did. A Scottish survey also found variable knowledge of health and social services (University of Aberdeen, 1984). A small project with carers of demented dependents found that carers did not know how to get help (Sanford, 1988). In an American study, Krout (1988) found general low levels of service awareness of elderly subjects particularly in rural areas.

There appears to be a good case for trying to improve poor consumer knowledge of services, but equally there is a need to evaluate the contribution to patient care that provision of information makes, and of the

best means to provide information (Gilleard, 1990).

The need for increased consumer involvement in the planning and provision of services has been argued. The main thrust of the influential Wagner report (National Institute of Social Work, 1988) was to increase involvement of residents in residential homes in the care process and in choosing a home. Studies have shown evidence of increased mortality when the frail elderly are relocated without their involvement in planning the move (Steinberg et al, 1986, Schulz & Brenner, 1977) but no such effect where they are involved (Grey, 1978).

Dementia will clearly limit the capacity of consumers for involvement in the planning and provision of services although it may be possible for a "citizen-advocate" to protect basic civil rights of demented consumers (King's Fund, 1986). An advocate might be an informal carer if there is one.

Carers of demented dependents are reported to want an active role in planning services (Pratt et al, 1987). This is supported by some professionals (Lodge & McReynolds, 1985). However, Cantley and Smith (1983) have reported lack of consumer input in the running of a psychogeriatric day hospital and McCullough (1989) has reported high perceived unmet needs for services by carers of the demented elderly.

### 5.2. Needs assessment in long-term care

In the United Kingdom, the most powerful voices in the planning and provision of health services are those of doctors and administrators (Evers, 1982). Doctors have been given responsibility to ration health care on the basis of assessed need (Cooper, 1975) but Buckley & Runciman (1985) in a thorough review of methods of professional health assessment of the elderly conclude that there is no agreed method, and Chamberlain (1973) found poor correlation between needs assessment of older people at home by health visitors with assessment in a clinic by specialists. On a world scale, there

appears to be a huge mismatch of resources to need. Even in affluent countries, unsophisticated but needed services such as home help, chiropody and dental services are inadequately provided (World Health Organization, 1982).

In geriatric practice, much attention has been given to measurement of disability as an indicator of need. An example of an imaginative method is that of Isaacs and Neville (1975) where subjects are categorised as needing long-term care where assistance or supervision is required for functional activity at short or infrequent intervals. The need for day care has also been evaluated according to disability (Tibbet & Tombs, 1981).

Wilkin and Hughes (1986) argue that disability as a measure of needs assessment ignores the concept of holistic care which involves a synthesis of professional judgements with the views of patients. This synthesis may be difficult to achieve.

For example, it has been shown that doctors fail to accurately reflect patients' perceptions of quality of life (Uhlmann et al, 1988). Nurses, too, are perceived by patients as failing to understand their emotional needs (Morle, 1984). Armstrong-Esther and Brown (1986) and Fielding (1979) found that nurses' attitudes to the elderly differ according to the setting in which they operate.

A stronger input of consumer opinion in the planning and provision of services might lead to improved matching of resources to need. It remains to be seen if consumers, even if encouraged to do so, will become more actively involved in the planning and provision of services (Phillison, 1990) and whether this will lead to better use of resources, reduced carer burden and improved quality of life of patients.

### 5.3 Market Forces

One strategy for increasing the role of the consumer which may be in line with current central government policy is to promote the expansion of private and voluntary care.

Research in the United States supports the view that increased supply of private nursing homes so that they are subject to market forces leads to improved quality of care, on the basis that consumers exercise rational choices in the selection of nursing homes (Nyman 1988a, 1989a). Where such choice is restricted, lower quality (based on violations of quality regulations) has been observed (Kosberg & Tobin, 1972; Nyman, 1985). Furthermore, when consumer choice is restricted by limiting the supply of nursing homes, nursing homes have been shown to admit less dependent patients (Feder & Scanlon, 1980; Willemain & Farber, 1976; Scanlon, 1980) and spend less on patient care (Nyman, 1988b), whereas where nursing homes compete for patients, they appeared to be more willing to accept heavily dependent patients at low rates of state-subsidy (Nyman, 1988c). Nevertheless, there have been reports about poor quality unregulated private nursing home care in the United States including an influential book by Valdeck (1980) which has led to calls for increased regulation by statutory bodies (Fottler et al, 1981).

Paradoxically, the effects of the proposed community care reforms in the United Kingdom (Secretaries of State for Health, Social Social Security, Wales and Scotland, 1989) may decrease consumer choice for patients. Patients in private nursing homes rapidly spend down to income support levels so that income is not sufficient to pay the current fees of 97% of private nursing home places (Godber & Higgins, 1990).

#### 5.4 Summary

There is a need for more information about consumer perceptions of services for the elderly. It appears that the elderly (and general public) prefer community to institutional care. Global satisfaction with services is high, but there are specific complaints. Knowledge of services is poor. There is little consumer involvement in the planning or provision of services. There is some evidence that professional needs assessment has resulted in poor matching of resources to need. An increased role for the consumer in the evaluation, planning and provision of services is the declared aim of central government proposals for reforms in health and social services, but it remains to be seen whether this will occur and research will be required to document its effects.

### 6. Audit

#### 6.1. Standards of care

Central government reforms for the health service (Secretaries of State for Health, Wales, Northern Ireland and Scotland, 1989) propose an expansion of audit in medical practice.

Audit focuses attention on standards of care (Royal College of General Practitioners, 1982). Standards may be set according to the framework of Donabedian (1966), which concentrates on structure, process and outcome. Structural criteria include the material, social and intellectual environment of care (e.g., facilities and staff qualifications), process criteria are the activities required to be undertaken to provide care (e.g., recording of clinical data) and outcome criteria are the objectives for the results of care. In this framework, there is a linear relationship between structure, process and outcome so that outcomes are included only if they are affected by structure and process of care. Equally, Evans (1983) argues that structure

and process are only important if they affect the outcome of care.

### 6.2 Improving quality of care

In order to improve practice, a five-stage audit cycle approach has been suggested where 1) standards are set by practitioners, 2) practice is observed, 3) comparison is made between standards and observed practice, 4) change is implemented, and 5) practice is re-observed (Fowkes, 1982).

This approach has been used in the United States in medical care for many years (Donabedian, 1966; Brown and Fleisher, 1971). Internal audit is founded on an educational approach (Coles, 1989). Feedback to practitioners needs to be maintained or practice often reverts to pre-audit levels (de Dombal et al, 1974).

Although medical audit is restricted by definition to clinical care, the audit cycle approach could be used to address wider aspects of quality assurance including professional performance, use of resources, minimisation of iatrogenesis and the production of desirable consumer-oriented outcomes (Scalley et al, 1988).

Expert bodies have recommended that audit activities should focus on consumer-oriented outcomes, such as patient satisfaction and quality of life (Royal College of Physicians of London, 1989; Association for the Study of Medical Education, 1990). This focus is in contrast to previous quality assurance in health care for the elderly. Between 1983 and 1986 the Department of Health and Social Security used 4 performance indicators to compare regional differences in health services for the elderly: length of hospital stay, the number of elderly who spend a very long time in hospital, use of day care, and the amount of district nursing care for the elderly (Department of Health and Social Security, 1988).

### 6.3 Summary

The more widespread use of audit will increase attention on the outcomes of care, including patient satisfaction and quality of life. Audit also provides a means to improve practice. An audit approach could be a powerful mechanism for improving the quality of life of the dependent elderly and their carers in long-term care.



## STATEMENT OF AIMS

The summaries in the literature review lay the foundation for the statements of aims and objectives.

In brief, the literature review reveals that there are deficiencies in long-term care services for the elderly in both the community and in institutions. The impact of dementia appears to be of particular importance for carer burden and provision of community and institutional services. There is concern about changing patterns of institutional care for the elderly, but much debate has failed to address the central issue, the quality of life of patients. Central government proposals for reform of health and social services promote a more consumer-oriented approach to delivery of care but there are doubts about whether this will be achieved, whether it will benefit consumers and of the resource implications. Furthermore, there has been little previous work in ascertaining the views of older people and their carers about long-term care services. The more widespread use of audit may provide a mechanism for changing long-term care services towards improving the quality of life of the dependent elderly and their carers.

The aims of this thesis are to describe the views of the dependent elderly and their carers about long-term care services, and explore ways in which a shift to a more consumer-oriented approach to the delivery of services might influence the outcomes of care.

Four questions are addressed:

- Q1. How do consumers view long-term care services?
- Q2. How can long-term care services be evaluated from a consumer perspective?
- Q3. How can a more consumer-oriented approach to long-term care service delivery be achieved?
- Q4. What might be the resource implications of a more consumer-oriented approach to service delivery?

### STUDIES

The specific objectives of the studies in the thesis are:-

#### Study 1.

- (1) To evaluate support for carers of the demented elderly by a primary care team using a formal system of audit having set the following standards:
  - a) the team should know of the existence of patients in the community who have symptomatic dementia;
  - b) carers should not have unmet needs for available services;
  - c) carers should be knowledgeable about dementia.

- (2) To describe carers' perceptions of services (knowledge, unmet needs).
- (3) To describe changes in the pattern of service delivery following intervention.
- (4) To describe changes in carers' psychological morbidity following intervention.

### Study 2.

- (1) To describe the perceptions of services (knowledge, unmet needs, benefit) of patients attending a geriatric day hospital.
- (2) To determine whether the level of support from services or carers is positively correlated with patient dependency.

### Study 3.

- (1) To describe carers' perceptions of unmet need for services and their ability to predict future needs for long-term institutional care at the time of admission to a geriatric assessment unit.
- (2) To determine whether carers' perceptions of unmet need, adequacy of formal and informal support and predictions of future need are associated with subsequent institutionalisation.

Study 4.

To determine whether change in life satisfaction of carers following institutionalisation of dependents is associated with proximity of patient and carer.

Study 5.

- (1) To describe and compare measures of quality of life of old people in private nursing homes and continuing care geriatric and psycho-geriatric wards.
- (2) To describe and compare other measures in these settings; patient dependency, staff morale and cost data.

Study 6.

- (1) To develop standards for long-term hospital care based on the views of patients.
- (2) To describe patients' views.
- (3) To compare patients' views with those of staff, and with actual practice.

The criteria used for the selection of study populations were dictated by opportunities for contact with patients and carers in primary care in Alva, Clackmannanshire and in hospital practice in Dundee.

Numerical data obtained was entered onto computer using the facilities of the Department of Medical Computing of the University of Dundee, and analysed with the Statsgraphics, Statistical Package (Statgraphics, 1988).

## STUDY 1

### An Audit of Primary Care Support for Carers of the Demented Elderly

#### Aims

The aims of this study were:

- (1) To evaluate support for carers of the demented elderly by a primary care team using a formal system of audit having set the following standards:
  - a) the team should know of the existence of patients in the community who have symptomatic dementia;
  - b) carers should not have unmet needs for available services;
  - c) carers should be knowledgeable about dementia.
- (2) To describe carers' perceptions of services (knowledge, unmet needs).
- (3) To describe changes in the pattern of service delivery following intervention.
- (4) To describe changes in carers' psychological morbidity following intervention.

#### Populations and Methods

Alva Medical Practice is an urban, six partner training practice with an attached nursing team, including a state enrolled nurse who has a specific responsibility for visiting and supporting approximately 600 persons aged over 75 years in the practice.

Each general practitioner and the state enrolled nurse were asked to list all elderly (75 years or greater) subjects who they suspected of having dementia and were living at home. Subjects in residential accommodation, nursing homes or hospitals were excluded.

A total of 12 subjects were identified by the general practitioners and a total of 27 subjects by the state enrolled nurse, whose list included the 12 subjects identified by the general practitioners. Two of the 27 subjects were in hospital and were therefore excluded.

A short mental status questionnaire (MSQ) (Jachuck et al, 1986), validated for use in primary care populations for screening for cognitive impairment, was administered to the 25 remaining subjects, case records were reviewed and an unstructured clinical examination was made in order to confirm the presence of cognitive impairment and to exclude the following alternative diagnoses for cognitive impairment: mental handicap, depression, acute confusional state, drug- or alcohol-associated confusion, anaemia and hypothyroidism.

Cognitive impairment was graded according to:

MSQ 0-3 = severe  
4-7 = moderate  
8-10 = mild  
11-13 = normal

The next of kin according to practice records was contacted and asked whether they were aware of a history of forgetfulness, confusion or behavioural disturbance and of the duration of symptoms.

A diagnosis of symptomatic dementia was made if the following criteria were fulfilled:

1. MSQ <11/13
2. Symptoms of at least 3 months duration
3. No alternative diagnosis for cognitive impairment

Given the difficulties associated with making the diagnosis of dementia during life, these criteria were chosen as the best which could be applied to identify subjects with a reasonable likelihood of having dementia and whom the primary care team might reasonably be expected to suspect of having dementia.

The results of the assessments are shown in Table 1.

Twenty-one of 25 subjects were found to have symptomatic dementia according to the criteria.

Three had alternative psychiatric diagnoses and one had apparently normal cognitive function.

The age-sex register of the practice was reviewed with the practice receptionists in order to determine the number of elderly subjects living at home at the time of the study.

There were 594 elderly subjects on the register. Of these, 60 were identified as either dead or in institutional care.

The primary care team had identified 21 subjects living at home with a confirmed diagnosis of symptomatic dementia from a sample of 534 potential subjects - a prevalence of symptomatic dementia of 3.9% in the <75 years age group.



Compared with previous population norms (Kay et al, 1964, 1970) this gives a low prevalence for dementia. It was therefore hypothesised that there would be a large number of subjects in the practice with symptomatic dementia who had not been identified by the primary care team.

It was not possible within logistic constraints to screen all 509 elderly subjects living at home who were not suspected as having dementia.

In order to estimate the prevalence of symptomatic dementia in the elderly population living at home who were not known to the primary care team, a sampling method was used to screen a proportion of this population.

It was considered feasible to screen 60 subjects. Six members of the nursing team undertook to screen 10 subjects each.

The first and every tenth subject on the age-sex register of 594 subjects, which runs alphabetically, were selected for screening. Subjects who were dead, institutionalised or on the list of subjects suspected to have dementia were excluded and, in their place, the subject immediately following the excluded subject was selected for screening.

No intentional bias was introduced by this sampling method and it does not appear likely that unintentional bias was introduced.

Letters were sent to each subject stating that a nurse would call and ask a few questions as part of a research project. A tear-off slip was provided to be signed and returned by the subject to the practice within two weeks if the subject did not wish to be interviewed (Appendix 1(a)). Nine slips were returned refusing consent, so 51 subjects were seen. If there was evidence of cognitive impairment (MSQ <11/13) the next of kin was asked whether they were aware of any history of forgetfulness, confusion or behavioural disturbance and medical review was undertaken to exclude alternative diagnoses. A diagnosis of symptomatic dementia was made if there was cognitive impairment, a history of symptoms of at least 3 months duration

and where no alternative diagnosis was evident.

Confidence limits for prevalence rates were calculated using appropriate statistical methods (Cochrane, 1963; Diem, 1962).

Following identification of subjects with symptomatic dementia an attempt was made to identify the person (relative, spouse, friend or neighbour) who provided most support for the demented subject. In most cases this person was the next of kin who had been interviewed for a history of symptoms of dementia in the demented subject.

Such carers were further interviewed if they fulfilled the following: 1) they provided support at least on a daily basis to the demented subject, or lived with the demented subject, 2) they did not provide professional care to the subject (e.g. home help).

Of the 22 subjects identified from survey or suspected list as having symptomatic dementia, three had no carer as defined above, one was on prolonged holiday during the study and one died.

Seventeen carers were therefore included as subjects for further interview.

Structured questionnaires were devised for the study. A knowledge questionnaire (Appendix 1(a)) listed 15 facts about symptomatic, prognostic and management aspects of dementia. Carers were asked to indicate which facts were known to them. A resource questionnaire (Appendix 1(a)) listed 17 resources (statutory, voluntary and fiscal) which were available to the demented elderly and their carers. The carers were asked to indicate which they were received and which they would like to receive. In addition, a stress questionnaire, validated for community studies (Goldberg, 1972) was issued to carers who were asked to return it to the practice in a pre-paid envelope. Five failed to return this.

Questionnaires were administered by a General Practice Trainee (IP) to 12 carers and by a part-time health visitor (AJ) to 5 carers. AJ was trained in the use of the questionnaires and was an observer during administration of the questionnaires by IP.

No tests of inter-rater reliability or repeatability of the questionnaires were undertaken, but as all questions were structured, poor reliability was not anticipated.

Following interview, carers were issued with a short booklet written for carers of the confused elderly (Age Concern Scotland, 1985). The carer's general practitioner was informed of the perceived unmet service needs of the carer.

Six weeks following first interview, carers were re-interviewed using the same questionnaires administered by the same interviewer. The level of statistical significance of changes in knowledge about dementia, resource use and perceived unmet resource needs between first and second interview were calculated using the Wilcoxon matched pairs non-parametric test.

## Results

The state-enrolled nurse identified 27 subjects with suspected dementia including the 12 subjects identified by the general practitioners.

The results of the assessment of the subjects with suspected dementia are shown in Table 1. The diagnosis of dementia was confirmed in 21/25 (84%). 3/25 (12%) had an alternative psychiatric diagnosis and 1/25 (4%) was normal. Where the diagnosis was confirmed, the majority (19/21) had moderate or severe cognitive impairment, whereas those with alternative diagnoses had only mild or no cognitive impairment.

The results of the survey of those thought not to have dementia are shown in Table 2. Only one subject was found to have symptomatic dementia. Review of practice records indicated that the subject was in fact known to the primary care team including the state-enrolled nurse as demented but had been overlooked when the primary care team listed the suspected demented elderly. Therefore, no person with symptomatic dementia was found on survey who was not already known to the primary care team as demented, but confidence limits are wide. There were a large number of subjects (17/51, 33/3%) with mild cognitive impairment, but without symptoms of dementia, in the survey group.

A summary of calculated prevalence rates for symptomatic dementia and for mild cognitive impairment without symptoms is shown in Table 3.

The mean age of the 17 elderly subjects with symptomatic dementia and support from a carer was 81.6 years (range 76-93 years). The majority of the carers were relatives of the demented patients - 4 were daughters, 4 husbands, 3 wives, 3 sons and one a sister; 2 were friends. Eight of the carers lived with the demented patients while the remaining 9 lived separately but none lived more than one mile from the demented patient.

Carers' knowledge about symptomatic, prognostic and management aspects of dementia before and after intervention is shown in Table 4. There was an increase in the carers' overall level of knowledge about dementia following intervention (Wilcoxon matched pairs signed ranks test,  $p < 0.001$ ).

There was little change in the use of resources by carers following intervention (Table 5). The principal changes were an increase in the use of respite admission and community nursing services, and a decrease in the use of meals on wheels and mobile alarm systems. One patient was in long-term institutional care at follow-up. The total number of resources used was 57 before intervention and 56 afterwards.

Resources which the carers felt they would like to receive before and after intervention are shown in Table 6. There was a decrease in the number of perceived unmet needs following intervention ( $p < 0.01$ ). The mean number of unmet needs per carer was 2.29 before intervention and 1.00 after.

The stress scores for the 12 carers who returned questionnaires were also significantly reduced ( $p < 0.01$ ). Scores were compared with normative population data for the general health questionnaire. Nine of 9 carers had scores which were indicative of significant psychiatric distress, called 'caseness', before intervention, and only 5 afterwards (Table 7).

### Discussion

In this study, 3 standards for audit were set. The first standard was that the team should know which patients in the community had symptomatic dementia. As only 3.9% of the elderly population with confirmed symptomatic dementia were identified from our suspect list, it was thought based on frequently quoted prevalence rates for dementia that there would be a large group not known to the primary care team (Kay et al, 1970). Surveying one in nine of the population would have identified some of this group and allowed an accurate estimate of the prevalence of dementia in the study population. However, the prevalence was lower than anticipated, though it is impossible to say precisely how low as insufficient numbers were screened to produce narrow confidence limits. Nevertheless, no elderly person was found with symptomatic dementia who was not already known to the primary care team. There was therefore no evidence that the team failed to meet Standard 1.

There were a large number of elderly with mild cognitive impairment, without symptoms, but it is not known what proportion would progress to dementia (Cooper & Bickel, 1984). The size of this group would vary

according to choice of screening instrument, or the cut-off point for case identification (Kay et al, 1990). As there are no established drug therapies for clinically useful treatment of the underlying processes in the common forms of dementia (Whalley, 1989), the emphasis in this study was to identify those subjects who had symptoms evident to their carers, rather than asymptomatic subjects. The large group with cognitive impairment, without symptoms, might require follow-up as an at-risk group, but this would create considerable workload and could create unintended negative effects for the carer-dependent relationship (Pollitt et al, 1989).

It is likely that the attachment to the practice of a nurse with specific responsibility for the elderly led the primary care team to know of the existence of many symptomatic demented elderly persons. She was able to identify all the subjects with suspected symptomatic dementia. Between them the general practitioners identified less than half of this group. The nurse had no training in mental health and did not use tests for cognitive impairment.

It has been shown that the attachment of a health visitor to a primary care team with specific responsibility for the elderly results in the identification of many problems not previously known to the team (Vetter et al, 1984). O'Conner et al (1988) in a study in 5 practices, found that district nurses were aware of many demented subjects not known to general practitioners.

Although there was no evidence that the primary care team failed to meet the first of the standards set to evaluate its support of the demented elderly (that they knew who had symptomatic dementia) the team were less effective when practice was compared against standards 2 and 3.

Overall knowledge of services was low prior to intervention, and although unmet needs were only modest, they were significantly reduced following intervention.

Some of these changes may have been artefactual. Knowledge levels might have increased simply by familiarity with the questionnaire. However, the impression was gained that carers were genuinely more knowledgeable, probably as a result of reading the information booklet about dementia.

Although no "non-intervention" control group was used in the study, the reduction in perceived unmet resource need was impressive. The positive responses of carers to being asked about their unmet needs (e.g. "I am so pleased someone is willing to listen to my views - they never did before") may have been, in itself, therapeutic. A genuine "non-intervention" control group might therefore be difficult to create.

Other possible explanations for the reduction in unmet needs include (1) the "Hawthorne" effect (Handy, 1985) (any change in practice produces a short-term perception of benefit), (2) increased knowledge or reassurance that needs were understood leading to greater carer confidence, and (3) a rationalisation of services following reporting of unmet needs to the general practitioner.

The last hypothesis is unlikely as there was little evidence of the general practitioners responding to reported needs.

The reduction in needs was not due to increased resource use in that the overall number of resources used was not increased. Clearly, however, some services are different from others in their importance for relief of burden and cost of provision. In spite of the methodological weakness of counting services as an index of service use, the study gives strong support to the view that paying attention to carers' needs does not lead to a flood of demand for services or the withdrawal of support by carers themselves (Kennie, 1986).

As for effects on carers' stress, only cautious conclusions are made as only 12 relatives returned questionnaires and there was no control group. However, the stress levels observed prior to intervention are similar to those observed in other studies with carers of the demented elderly (Gilleard et al, 1984a; Levin et al, 1983) and the reduction in stress is similar to that observed in a study of the effects of day hospital intervention (Gilleard et al, 1984c). Therefore, the effects of the audit appeared to result in psychological benefit to carers.

It is suggested that there is a need to improve case-finding for undetected problems in the elderly (Buckley & Williamson, 1988). In the Alva practice, it is unlikely that improved case-finding would increase the effectiveness of support by the team for carers of the demented elderly as they were already known to the nurse with special responsibility for the elderly. What appeared to be required was to translate that knowledge into a more focused attention to carers' needs. The positive outcomes of intervention in the study suggest that such an approach was worthwhile, particularly as there was no evidence of a resultant increase in overall resource use. Although this study deals with a selected group of demented patients, the results support the policy of the Scottish Home and Health Department (1980b) that there should be a more imaginative use of district nursing and health visitor services to contact the at-risk elderly, to assess need and refer for services.



## STUDY 2

### Perceptions of Services of Patients Attending a Geriatric Day Hospital

#### Aims

The aims of this study were:

- (1) To describe the perceptions of services (knowledge, unmet needs, benefit) of patients attending a geriatric day hospital.
- (2) To determine whether level of support from services and carers is positively correlated with patient dependency.

#### Populations and Methods

Subjects were patients attending a geriatric day hospital during a four week period. The following exclusion criteria were applied:

- (1) Patients with evidence of moderate or severe cognitive impairment. (Case records of patients were reviewed. All contained data about cognitive status using a questionnaire validated for use in hospital (Wilson & Brass, 1973). A mental score (MSQ of <7/10) was taken to suggest moderate to severe impairment).
- (2) Patients who failed to attend day hospital on scheduled interview day.

Forty-seven subjects were included following application of these criteria.

Subjects were interviewed by a medical student. The questionnaire (Appendix 1(b)) was adapted from the questionnaires used in study 1. There was an expansion of the list of resources to include resources appropriate for

non-demented subjects. Subjects were asked to indicate which they had heard of (knowledge of resources), which they got (resource use), which they would like but were not getting (perceived unmet resource needs) and, for those which they got, to indicate their perceptions of benefit by choosing one point on a five point scale between two extremes labelled "no benefit whatsoever" and "the most benefit possible". Subjects were also asked whether they lived with a carer, lived alone with daily support or lived alone with less than daily support from a carer. In addition, the age, sex and mental status (MSQ) of subjects was recorded following review of medical case notes. The functional status of subjects was recorded following review of nursing notes which classified functional status according to the opinion of the nurse about whether the patient was independent or not independent in continence, dressing, mobility, shopping and cooking.

The Spearman rank correlation test was used to determine whether number of resources known, received or wanted, or level of perceived benefit were correlated with age, sex or level of dependency and to determine whether level of support from services or carers was correlated with patient dependency.

## Results

No patients were in receipt of any of the psychiatric services listed on the questionnaire (psychologist, psychiatrist, psychogeriatric day hospital, psychiatric hospital respite and psychogeriatric hospital long-term care) and no patients perceived a need for support from these sources.

Table 8 (sources of support) shows the level of non-psychiatric service use, patients' knowledge of services, unmet service needs and perceived benefit from services.

The number and proportion of patients receiving each service is shown in column (a). Although there was a full-time social worker in the Day Hospital, only 5 patients (10.6%) received support from this source.

Patients' knowledge of services is expressed in 2 ways: services known, and services not known as a proportion of those not received. Only home helps and general practitioners were known by over 90% of patients who had not received the service in the previous month. Over 50% of patients did not know of the following services: hospital respite, other voluntary support, relative support groups, private nursing, private help, night sitters, long-term hospital care, laundry service, health visitors, crossroads care attendant scheme, lunch clubs, day centres and private nursing homes.

The level of unmet need for services is shown as the proportion who needed a service they were not currently receiving (column (d)).

The mean number of unmet service needs per patient was modest (0.81). Excluding services where only one subject expressed an unmet need, services which were most needed were: Day centre (19.8%), physiotherapy (14.3%), social club (13.3%), home help (7.1%), laundry service (7%), and the crossroads care attendant scheme (6.4%).

There were a total of 5 unmet needs for health services, 2 for private services and 31 for social services. In spite of a relatively high level of unmet need for social services, only one patient perceived the need for support from a social worker.

Of services received by at least 5 patients, the rank order of perceived benefit of services was: Day Hospital itself, occupational therapy, physiotherapy, home help, sheltered housing, district nurse, meals on wheels, minister/priest, general practitioner, social worker.

The level of physical and social functioning was not significantly associated with either the level of support from services or carers. However, the amount of service support was inversely associated with the level of carer support (Spearman rank correlation  $r = .3838$ ,  $p < 0.01$ ).

The number of services known to patients was not significantly associated with patients' age, sex, functioning or level of support from carers or number of services received.

The number of perceived unmet service needs was not significantly associated with patients' age, sex, functioning or level of support from informal carers or number of services received.

The level of perceived service benefit was not significantly associated with patients' age, functioning or level of support from carers or number of services received, but was weakly associated with the number of services known to patients (Spearman rank correlation  $r = .2967$ ,  $p < 0.05$ ), and with male sex ( $r = .3143$ ,  $p < 0.05$ ).

## Discussion

The first aim of this study was to describe the perceptions of long-term care services of elderly patients attending a geriatric day hospital. The fact that three patients had not heard of general practitioner services raises doubts about the validity of the responses to the knowledge questionnaire. It would seem reasonable to assume that all cognitively-intact adults would have heard about general practitioners. It is possible that patients had interpreted the question in the sense of whether general practitioners provided a service which was relevant to their needs.

In spite of doubts about the validity of the questionnaire, the overall pattern of reported knowledge about services is interesting.

Knowledge of private services was poor. Fewer than 50% of patients had heard of private nursing homes, home nursing, home care or night sitters. Salvage et al (1989) found that 27% of 251 randomly selected elderly people had not heard of private rest homes and 15% had not heard of local authority homes. Lack of knowledge of private services in Dundee may reflect local socio-economic and cultural factors. There was a corresponding lack of use of private services among the patients.

Respite and support for relatives is a recognised function of day hospitals (Brocklehurst & Tucker, 1980). However, few patients had heard of other local services which provide respite or support to relatives such as the Crossroads care attendant scheme, relative support groups and geriatric hospital respite. Lack of knowledge about the laundry service and health visitors may reflect the lack of relevance of these services to some patients needs.

Unmet needs were mostly for social services, but only one patient perceived the need for support from a social worker, and only 5 patients were supported by a social worker. There appeared to be a need, therefore, to educate patients about the role of the social worker.

Patients' perceptions of benefit were also interesting. The day hospital itself, physiotherapy, occupational therapy and home help were highly rated. By comparison, the general practitioner and social worker were poorly rated. General practitioners are thought to be highly regarded by the public (Cartwright, 1967; Cartwright & Anderson, 1981). Low perceptions of benefit could be an indicator of dissatisfaction among patients about general practitioners and social workers as gatekeepers to resources.



The second aim of this study was to determine whether support from services and carers was associated with patient dependency. No association was found, but support from carers was inversely correlated with the number of services received suggesting that carer support may substitute for formal services.

This may reflect poor spread of dependency in the day hospital population, but raises the possibility of poor matching of resources to need on the basis of dependency.

Overall, a picture emerges of poor patient knowledge about services, with unmet need for social services, dissatisfaction with support from general practitioners and social workers as the main gatekeepers to services, and no evidence of targeting of services on the basis of dependency needs. Improvement in patients' awareness of services and in the provision of social services could be addressed by a social worker who would appear to have ample scope for social work case management in this geriatric day hospital population.

### STUDY 3

#### Carers' Perceptions of Services and the Outcome of Acute Hospital Care for the Elderly

##### Aims

The aims of this study were:

- (1) To describe carers' perceptions of unmet need for services and their ability to predict future need for long-term institutional care at the time of admission to a geriatric assessment unit.
- (2) To determine whether carers' perceptions of unmet need, adequacy of formal and informal support and predictions of future need are associated with subsequent long-term institutionalisation of patients.

##### Population and Methods

Subjects were carers of patients admitted acutely to a female geriatric assessment ward during a 4 month period. The following exclusion criteria were applied:

- 1) Where no carer was contacted within one week of admission,
- 2) When patients were admitted for planned respite or shared care,
- 3) Carers who had less than weekly contact with the patient,
- 4) Carers who refused to participate in the study,
- 5) Patients admitted from institutional care.

Relatives visiting patients within one week of admission to the unit were contacted by ward nursing and medical staff and asked who provided most informal support to the patient prior to admission. Carers identified as

providing most support were contacted and were interviewed using a structured questionnaire (Appendix 1(c)). In total 47 carers were interviewed.

The questionnaire was adapted from the resource questionnaire used in study 2. Carers were asked which services the patient got (resource use), and which they would like the patient to get but were not receiving (perceived unmet resource need). In addition, they were asked to rate their overall level of satisfaction with support from services and from other family members, their perceptions of the quality of their relationship with the dependent prior to their dependent becoming ill, the quality of their relationship now, their perceptions of their health, and whether their health had suffered because of having to care for their dependent. The age, sex, and relationship of the carer to the patient was recorded. Case notes were reviewed for patient's age, prior placement and mental status using a simple mental status questionnaire (Wilson & Brass, 1973). On discharge, or if it was decided at case conference that the patient would need long-term care in hospital, the discharge placement status of the patient was recorded. (Died, home alone, home with carer, residential care, nursing home, long-term hospital care).

Questionnaires were administered by a Senior Registrar in Geriatric Medicine (IP) or by resident house officers on the assessment ward depending on who was present on the ward when the carer was available for interview.

The Spearman Rank Correlation non-parametric test, and the chi-squared test with Yates correction, were used to determine the level of statistical significance of associations between discharge placement status and factors which were thought to be predictive of placement.



## Results

The level of service use and unmet service needs as perceived by carers is shown in Table 9. The level of unmet need is shown as the proportion who needed a service they were not currently receiving.

The mean number of unmet needs was 2.08 per patient. Although general practitioners and district nurses were among the services most widely used by patients prior to admission, they were also the services for which there was the highest unmet need (42.1% and 43.4% respectively). A high prevalence of unmet need was also found for meals on wheels (30%), sheltered housing (25%), home help (21.2%), health visitor (19%) and day centre (14.6%).

Five carers failed to indicate their expectations of discharge placement. Of the 42 patients where carers did indicate their expectations, 7 patients subsequently died. Of the remaining 35 patients, 8 went on to long-term institutionalisation and 29 were discharged home.

Table 10 shows the predicted placement outcome compared with actual outcome. Carers' predictions of the need for long-term institutional care were relatively high (13/35). Carers predicted institutionalisation in all cases where institutionalisation occurred, but also in 5 cases where patients returned home. The accuracy of the prediction was highly significant to a 2x2 chi-squared test ( $p < 0.001$ ).

For other measures which might have been predictive of institutionalisation, no significant statistical association was found (Table 11).

## Discussion

The relatively high level of perceived unmet needs for services (mean 2.08) suggests that carers felt their dependents were inadequately supported prior to hospitalisation.

This appeared to be particularly focused on the primary care team (general practitioner, district nurse and health visitor). This may relate to the fact that all patients were admitted as medical emergencies, where carers might have thought that earlier detection of illness and intervention by the primary care team could have prevented admission, a view which is commonly expressed in this context. It is not possible to determine from the data whether such a view has any factual basis.

No evidence was found that patients were more likely to be institutionalised if relatives' perceptions of prior support from services suggested poor support (high number of unmet needs, low satisfaction with support from services or low satisfaction with family support). Nor was the level of prior support (number of services), carers' age or perceived health, patients' age or mental status associated with subsequent institutionalisation. That prior support was not associated with institutionalisation is consistent with the results of a Danish study (Hendrikson et al, 1989) where enhanced community support to the elderly led to decreased hospitalisation but no difference in length of hospital stay or subsequent placement of hospitalised subjects between intervention and control groups.

Small sample size may have prevented detection of a significant association between institutionalisation and prior level and perceived adequacy of support. Also, the severity of the medical crisis leading to admission might have swamped other variables as a predictor of institutionalisation. Nonetheless, no evidence is found in this study that the amount or perceived adequacy of support in the community reduces the likelihood of permanent institutionalisation of an elderly dependent admitted to acute hospital care. This does not exclude the possibility that community support reduces the likelihood of institutionalisation by other mechanisms such as direct admission to long-term institutional care.

The observation that carers' perceptions of the need for institutionalisation were predictive of that outcome was noted also in a survey from France (Roudot-Thoraval et al, 1987). However, carers appeared to overestimate the likelihood of institutionalisation. Thus, the assessment unit appeared to serve a gate-keeping function by transferring some but not all patients to long-term institutional care where carers predicted that outcome. Unfortunately, the study failed to identify factors in the level or perceived adequacy of prior support which could have formed the basis for deciding which patients would require long-term institutional care.

Finally, the study clearly highlights the ability of some carers to advocate what is required on behalf of their dependent relatives; however, further work is needed to determine the reasons for the mismatches between carers' and professionals' predictions of the need for institutional care.

#### STUDY 4

#### Change in Life Satisfaction of Carers Following Institutionalisation of

#### Dependents

##### Aims

The aim of this study was:

To determine whether change in life satisfaction of carers following institutionalisation of dependents is associated with the proximity of patient to carer.

##### Populations and Methods

Subjects were carers who visited patients in long-term geriatric hospital care wards in Dundee.

It was intended to recruit up to 120 subjects. Ten questionnaires were left on each of the 12 long term geriatric wards in Dundee. Nurses were asked to issue questionnaires to visiting carers and to ask carers to complete and return the questionnaire. Completed questionnaires were retrieved for analysis after 2 weeks.

Of the 120 questionnaires, 81 were issued, 39 were not issued either because too few carers visited the wards during the period or because nursing staff failed to issue questionnaires to visiting carers. Thirteen questionnaires were not returned or were unsuitable for analysis by failure to complete data on life satisfaction. Sixty-eight questionnaires were suitable for analysis of which 6 were only partially complete because of omission of data on length of institutionalisation.

The questionnaire (Appendix 1(d)) contained details of the carer's age, sex and relationship to the patient, prior contact with the patient (lived with, lived separately with daily support, less than daily support), life

satisfaction prior to the patient's institutionalisation and current life satisfaction using a simple questionnaire adapted from Peace et al (1979).

The two indices of proximity of patient to carer were: the amount of prior contact, and the relationship to the patient.

The Wilcoxon matched pairs non-parametric test was used to determine the level of statistical significance for change in life satisfaction of carers following institutionalisation of patients, and to determine whether change in life satisfaction was statistically associated with the age of patients or carers or with duration in institutional care. The chi-squared test with Yates correction was used to determine whether change in the satisfaction was associated with the sex of patients or carers, the relationship between patient and carer or amount of prior contact according to whether life satisfaction improved, deteriorated or remained the same.

### Results

The age of patients was 61 to 97 years with a mean of 83.3. Twenty-two male and 48 female carers returned questionnaires suitable for analysis. Eight were spouses of the patient, 41 were children and 19 were other family members. Nineteen had lived with the patient prior to institutionalisation. Nineteen had provided daily support to the patient and 30 had provided less than daily support. Patients had been in permanent institutionalisation for a period of between one and 386 months.

Overall there was a significant improvement in reported current life satisfaction compared with previous life satisfaction prior to institutionalisation (Wilcoxon signed ranks parametric test,  $p < 0.01$ ). Twenty-two carers reported improvement, 11 reported a deterioration and 35 no change. Change in life satisfaction was not significantly associated with the sex of

the carer ( $p < .3705$ ), age of the carer ( $p < .4148$ ), or the duration of institutionalisation ( $p < .1546$ ).

However spouses and children were more likely than other relatives to report improved life satisfaction following institutionalisation ( $p < 0.001$ ) (Table 12). Twenty-two of 49 spouses or children reported improved life satisfaction. Of 19 'other relatives', none reported improved life satisfaction.

Carers who had daily contact or lived with patients prior to institutionalisation were more likely to report improved life satisfaction following institutionalisation than carers who provided weekly or less than weekly support ( $p < 0.05$ ) (Table 13).

### Discussion

The aim of this study was to determine whether a change in the life satisfaction of carers is associated with proximity of patient to carer. A closer relationship between carer and patient and a greater amount of prior contact with patients were both associated with a greater improvement in life satisfaction. These differences are not explained on the basis of age or sex of carers of patients or duration of institutionalisation. There was a good spread of data for all these variables so that a relationship would be expected to be found if one existed. Therefore, the impact of institutionalisation of a patient on life satisfaction of a carer appears to be positively associated with the proximity of patient to carer, and the impact is towards improvement in life satisfaction of the carer. This would be expected if carers had been burdened by their role, and institutionalisation brought about relief of burden.

Although Chenoweth (1986), Colerick and George (1986) and Jones (1986) all found that institutionalisation of a patient produced its own stresses for carers, the results of this study suggest that life satisfaction is

likely to improve life satisfaction for carers who were close to patients. The discrepancy between these conclusions may be due to the timing of data recording. Studies immediately following institutionalisation will pick up short-term psychological effects which may well be negative at a time of crisis and adjustment, whereas a later period of data collection will pick up effects following a period of adjustment.

Although central government policy is to promote community rather than institutional care, a balance needs to be struck between the effects of institutionalisation on the quality of life of carers as well as patients. This calls for a value judgement which should be underpinned by research about the effects of institutionalisation on patients and carers. Ideally, prospective long-term studies of the effects of institutionalisation on patients' and carers' quality of life is required, but this simple retrospective study supports a beneficial effect for carers.

## STUDY 5

### A Comparative Study of Private Nursing Home and Long-term Hospital Care for the Elderly

#### Aims

The aims of this study were:

- (1) To describe and compare measures of quality of life of old people in private nursing homes and continuing care geriatric and psychogeriatric wards.
- (2) To describe and compare other measures in these settings; patient dependency, staff morale and cost data.

#### Populations and Methods

The setting for this study was the long-term institutional care sector for the elderly in Dundee. All continuing care wards of the departments of geriatric and psychogeriatric medicine and the 3 private nursing homes which serve the City of Dundee were examined. Unfortunately, access to local authority homes was refused by the Social Work Department.

Subjects were the charge nurses and officers-in-charge of each home and ward, and patients and nurses present during visits to each ward or home.

Patients were interviewed for cognitive impairment using a simple mental status questionnaire (MSQ) (Wilson & Brass, 1973). There were 58 nursing home patients. Four were too ill for interview and one refused. Of 192 geriatric patients, 12 were too ill for interview and one refused. All 186 psychogeriatric patients were fit for interview. Ten nursing home patients,



35 geriatric patients and 3 psychogeriatric patients had an MSQ >7/10. With the exception of the psychogeriatric patients, whose numbers were too small to yield useful data, this group were further interviewed for patient morale measures (Appendix 1(e)). Thirty-six geriatric, 29 psychogeriatric and 23 nursing home staff were interviewed for staff morale (Appendix 1(e)). No patients or staff refused interview.

Charge nurses and officers-in-charge were interviewed for dependency of patients excluding those with acute illness using validated questionnaires for physical disability (Katz et al, 1970) and social disruption (SD) using a sub-component of the Clifton Assessment Procedure for the Elderly (Pattie & Gilleard, 1975) as an index of behavioural disturbance. The Katz scale is intended to categorise patients into hierarchical levels of overall disability. However, it was found that many patients did not fit into the recognised categories. Therefore, disability of patients was compared according to the proportion of patients independent according to the Katz rating in each of the 6 activities of daily living assessed: bathing, feeding, dressing, toileting, transfers and continence.

Charge nurses and officers-in-charge were also interviewed for aspects of regime and environment (Appendix 1(e)).

Questionnaires were developed in a pilot study (Appendix 2) and derived from extensive work by Peace et al (1979) for evaluation of quality of life in residential care. All interviews were conducted by a research assistant (LB), who had a background in market research, or by a senior registrar in geriatric medicine (IP). Despite efforts to ensure standardisation of interview technique and the use of structured questionnaires, inter-observer bias cannot be excluded.

Economic data was obtained from Tayside Health Board and the Common Services Agency for Scotland (correct at 31 March 1988). These sources gave precise figures for the overall and itemised costs per patient week specific for long-term care geriatric wards in Dundee and do not reflect acute or rehabilitation costs which are documented separately. Information was not available for psychogeriatric ward costs. Costs of care in geriatric wards were compared with the costs of supporting fully-supplemented patients in private nursing homes and account was taken of differences in pension contributions to care. Available data do not allow calculation of medical and pharmacy costs in private nursing homes; therefore, these costs, which are known for long-term geriatric patients, have been deducted from hospital costs to allow valid comparison.

The level of statistical significance of difference between the settings for the proportion of patients independent of each activity of daily living was determined using the chi-squared test with Yates correction.

The Mann-Whitney pairs non-parametric test was used to determine the level of statistical significance of difference between settings for patient morale, nurse morale, regime and environment measures.

### Results

A greater proportion of psychogeriatric patients had evidence of cognitive impairment (MSQ <7/10) than either nursing home ( $X^2 = 20.64$ ,  $p < 0.001$ ) or geriatric patients ( $X^2 = 18.86$ ,  $p < 0.001$ ), and a greater proportion of psychogeriatric patients had evidence of behavioural disturbance (SD <10/10) than either nursing home ( $X^2 = 21.7$ ,  $p < 0.001$ ) or geriatric

patients ( $X^2 = 82.95$ ,  $p < 0.001$ ). There was no significant difference for these measures between nursing home and geriatric patients, although there was a trend towards more patients with behavioural disturbance in nursing homes ( $X^2 = 3.399$ ,  $p = 0.06$ ) (Table 14). In both nursing homes and geriatric wards there was a high prevalence of cognitive impairment in assessed patients (nursing homes: 81%; geriatric wards: 88%).

Psychogeriatric patients were significantly more dependent than geriatric patients in bathing ( $X^2 = 25.24$ ,  $p < 0.001$ ), dressing ( $X^2 = 25.10$ ,  $p < 0.001$ ) and continence ( $X^2 = 12.51$ ,  $p < 0.001$ ) but less dependent in toileting ( $X^2 = 8.995$ ,  $p < 0.01$ ) and transferring ( $X^2 = 44.93$ ,  $p < 0.001$ ) (Table 15).

Psychogeriatric patients were significantly more dependent than nursing home patients in bathing ( $X^2 = 46.55$ ,  $p < 0.001$ ), dressing ( $X^2 = 12.59$ ,  $p < 0.001$ ), continence ( $X^2 = 20.94$ ,  $p < 0.001$ ) and in feeding ( $X^2 = 9.913$ ,  $p < 0.01$ ) but less dependent in transferring ( $X^2 = 13.58$ ,  $p < 0.001$ ) (Table 15).

There was a trend towards greater dependency for all measures in geriatric patients compared with nursing home patients but this was only significant for feeding ( $X^2 = 4.904$ ,  $p < 0.05$ ) and bathing ( $X^2 = 3.96$ ,  $p < 0.05$ ) (Table 15).

There were no significant differences in patient worries or change in life satisfaction between nursing home and geriatric patients but geriatric patients were significantly more dissatisfied with staff ( $p < 0.05$ ) (Table 16).

There were large variations between homes and between wards in measures of regime and environment, and considerable overlap between the 3 settings although scores for space were higher in nursing homes (Table 17).

Psychogeriatric wards had significantly higher scores for architectural choice (an index of homeliness) ( $p < 0.001$ ), staff facilities ( $p < 0.01$ ), aids to orientation ( $p < 0.05$ ), and socio-recreational aids ( $p < 0.01$ ) than geriatric wards but a lower score for safety ( $p < 0.01$ ).

Nursing home staff had significantly greater job satisfaction than either geriatric staff ( $p < 0.01$ ) or psychogeriatric staff ( $p < 0.05$ ). Psychological well-being of nursing staff was significantly lower in geriatric wards than in either nursing homes ( $p < 0.05$ ) or psychogeriatric wards ( $p < 0.01$ ). Psychogeriatric staff had significantly more worries than nursing home staff ( $p < 0.05$ ) (Table 18).

Nursing home care revenue costs appeared considerably cheaper than hospital costs equivalent to over £100,000 per year for a 20 patient facility (Table 19).

### Discussion

The aims of this study were to describe and compare quality of life and other measures in long-term geriatric and psychogeriatric hospital wards and private nursing homes. A large number of measures were applied to relatively small populations. The chance of spurious findings were high and conclusions were tentative. Furthermore, the nursing homes in this study were small ones, and may differ in several respects from the larger nursing homes of the type that may become more fashionable because of financial reasons. Nevertheless, this is the first British study to systematically examine quality of life and related measures in these three settings. Also, the study was undertaken at a time of change and uncertainty about policy for institutional care in the United Kingdom, where information about the outcome of care is urgently required (Day & Klein, 1988). The results complement previous research in local authority residential homes (Willcocks et al, 1982). Furthermore, as all wards and homes serving a single city were visited, a representative picture for a defined geographic community is presented. The study raises questions which should be addressed in other centres in order to determine the generality of findings.

The use of structured questionnaires facilitated reliable collection of data about regime and environment, staff and patient morale and patient dependency. An alternative approach would be to use qualitative techniques such as the non-participant observer approach used by Clarke and Bowling (1989) in their comparison of quality of life in 2 private nursing homes and one long-term care hospital ward. Such an approach is labour-intensive and would have been more difficult to apply to the larger population in this study. Nevertheless, different insights are revealed by each approach and findings in this study are complementary to those obtained by a qualitative approach.

Patient self-report dissatisfaction with staff was significantly higher in geriatric hospital patients than nursing home patients. As this result is based on small numbers and no significant differences were found for 2 other measures of patient morale, it would be wrong to make too much of this finding. On the other hand, staff morale was also higher in nursing home staff than hospital staff. Low patient satisfaction with staff might be related to low staff morale.

Lower staff morale in hospital staff might be due to differences in the type of nurse attracted to hospital or nursing home care, including factors such as age, experience or personality (Livingston & Livingston, 1984). There could also be effects of difference in terms and conditions of service, management-staff relationships (Stryker, 1982; Waxman et al, 1984) or physical environment (Watson & Anderson, 1987). Fringe benefits rather than salary may be more important for morale (Halbur, 1983). Informal discussion with nurses revealed that hospital staff complain about excess bureaucracy and nursing home staff appreciate the flexibility in their conditions of service, especially in their working hours.

Higher staff morale in nursing homes would have important implications for the development of long-term care services for the elderly if confirmed by further study in larger populations.

Apart from their being more space in the nursing homes, the hospital and nursing home settings were characterised by large variation between wards and between homes for measures of regime and environment and overlap between the settings. It appears, therefore, that regime and environment can be shaped at the level of individual homes and wards towards improving quality of life, a conclusion which is supported by the report of Clarke & Bowling (1989). The large variation between wards and between homes could stimulate some wards and homes to emulate the high achievers. As scores for each measure are derived from a composite of items, it would be necessary to examine individual items if changes in practice are planned.

The cost data show that private nursing home care costs less to the tax payer than hospital care. The cost comparisons suggest a saving in excess of £100,000 per annum in revenue costs alone for a hypothetical 20-bedded unit. However, the cost data do not form the basis of an economic appraisal as opportunity costs and other factors were not taken into account. Furthermore, savings could be more apparent than real if, in the absence of pre-admission assessment, patients were inappropriately placed. Nursing homes may select less dependent patients to ease the burden and possibly the costs of care, and may "subsidise" state-supplemented patients with other patients paying for their care at higher rates, or by surcharging patients above DHSS supplementation.

The comparison of dependency between nursing home and hospital is in accord with previous studies which suggest that, although private nursing homes contribute towards care of the dependent elderly who would otherwise require long-term geriatric hospital care (Bennett, 1986), on the whole, geriatric hospital wards contain a greater proportion of the more disabled patients than private nursing homes (Capewell et al, 1986).

More surprisingly, there was a high prevalence of physical disability in psychogeriatric compared with geriatric patients particularly in bathing, dressing and incontinence. This could be due to a number of factors including: failure of rehabilitation practice in psychogeriatric wards leading to unnecessary dependency; physical disability as a consequence of severe mental illness; or from coexisting pathology. A previous study in Dundee found that disability in demented patients in long-term care was the result of coexisting pathology (MacLennan et al, 1987).

There was also a high prevalence of cognitive impairment in geriatric patients consistent with other reports (Bond et al, 1989a; Hodkinson et al, 1988).

There seems to be a need to rethink policy about the boundary between long-term geriatric and psychogeriatric care. Although there is a case to be made for segregating patients with special needs, such as those with severe dementia (Norman, 1987b), or the small proportion of cognitively-intact patients, a common administrative structure shared by geriatrics and psychogeriatrics has been suggested (Godber, 1987) and would seem more sensible than current arrangements given the overlap in dependency. A preliminary report demonstrates the feasibility of such an approach (Namdaran et al, 1989).

Regional variations in the provision of institutional services (Laing, 1985) may result in differing case-mix between settings. However, with the promotion of a pluralistic approach to institutional care provision and with separation of the functions of the purchaser from the provider (Secretaries of State for Social Security, Wales, Northern Ireland and Scotland, 1989), a rational basis for selecting care will be required. Ideally professional rivalries should not obscure the central issue, which is the quality of life of patients (Evans, 1989). The approach adopted in this study goes some way towards including quality of life in an evaluation of institutional care services. It may be a useful model for those concerned with the purchase of care.



## STUDY 6

### Setting Standards for Long-term Hospital Care

#### Aim

The aims of this study were:

- (1) To develop standards for long-term hospital care based on the views of patients.
- (2) To describe patients' views.
- (3) To compare patients' views with those of staff, and with actual practice.

#### Populations and Methods

Subjects were patients and nursing staff in the 12 long-term care geriatric hospital wards in Dundee. Each ward was visited once.

Patients had been assessed previously for cognitive impairment using a simple mental status questionnaire (Wilson & Brass, 1973). Those with MSQ less than 7/10 were excluded, leaving 35 with MSQ of 7/10 or more. Of these, 7 had intercurrent illness and were also excluded. Twenty-eight patients were interviewed. The 2 most senior trained nursing staff present when each ward was visited were also interviewed. On 2 wards, only one trained nurse was present during the visit. Therefore, only 22 nursing staff were interviewed. All interviews were conducted by a medical student (SM), using a schedule of questionnaires.

The schedule was derived from questionnaires used in the previous study for evaluation of regime and environment in hospital. There was a total of 129 statements. In this study nurses and patients in long-term geriatric hospital wards were asked to indicate their preferences for ward regime by answering the question "Do you think it is appropriate that . . .?", followed by each statement. Subjects could indicate Yes, No or Don't Know.

A pilot study with 4 staff and 4 patients on 2 wards revealed that the 129 statement questionnaire was too long for patients who lost concentration and became uncooperative about half-way through the questionnaire. Furthermore, staff suggested that many statements (e.g. about the provision of prosthetic aids) were of a too technical nature for patients. A second, shorter questionnaire (Appendix 1(f)) was compiled of 59 statements by elimination of statements which were thought to be repetitious or too technical. For 2 statements about space in bed and public areas, subjects were asked "Do you think there is adequate space in . . .?" rather than "Do you think it is appropriate that . . .?" The shorter questionnaire was applied to all subjects and was successfully completed. There were few "Don't Know" responses. These were classed as "no" responses for the purpose of data analysis, as the emphasis of the study was to identify positive preferences.

The level of statistical significance between the proportion of staff and patients who thought each statement appropriate was determined using the Chi-squared test with Yates correction.

## Results

For the 59 statements, the preferences of staff and patients compared with each other and with actual ward practice are shown in Table 20 in rank order of the proportion of patients in favour.

A greater proportion of staff than patients were in favour of most aspects of regime and environment, and this was statistically significant for 17 of 59 statements (Table 21). In addition, significantly fewer nursing staff than patients thought there was adequate space in either the sitting/dining areas ( $p < 0.05$ ) or bed areas ( $p < 0.01$ ).

Patient preferences were therefore modest compared with staff preferences, but ward practice failed to reflect patient preferences for many statements (Table 22).

Twenty-six standards were set for regime and environment where a majority of staff and patients were in favour (Table 23). These standards are grouped according to domains of regime and environment.

### Discussion

Although patients and staff had different views about long-term hospital care (in general patients had lower expectations), it was possible to set a manageable number of standards based on a consensus of the views of patients and staff about the same aspects of regime and environment.

There are limitations to the generality of the findings because of small sample size and geographic location. Nor was it possible to obtain the views of the majority of patients, mainly because of cognitive impairment. However, most standards, if implemented, would increase opportunities rather than impose practice, with the potential for improving quality of life for all patients.

Alternatively, a case could be made to segregate patients with cognitive impairment, although there is the danger that their interests would be even further neglected (Meacher, 1972).

The views of higher management were not sought, but as the majority of ward staff were in favour of standards set, the task for management to implement change is facilitated.

Relatives of patients are another group whose views are important. An attempt was made to interview relatives, but so few were present when wards were visited that insufficient data was available for meaningful comment.

A further criticism of the method for setting standards would be that implementation might lead to only marginal quality of life benefits. This depends on what is meant by quality of life. On the one hand, use of instruments such as the quality-adjusted life year (QALY) are insufficiently sensitive in this setting (Donaldson et al, 1988). On the other hand, little things mean a lot in long-term institutional care, so that simple changes such as the provision of a telephone for patients' private use could make a great difference for some patients.

Much of geriatric practice has to do with creating a climate of therapeutic optimism in the face of negative expectations about what can be achieved for the elderly. Negative expectations may be most pronounced amongst the elderly themselves (Tinker, 1981) which may explain why staff had higher expectations. However, the approach used to set standards in this study helps to create a challenge which can be met, and is oriented towards the perceived needs of patients.

Low patient expectations might also be due to the effects of institutionalisation (Goffman, 1961). Few patients thought it was appropriate to get up when they wished, to get individual attention, to have single rooms or to have a say in the general organisation of the ward. In the context of low expectations, the case to meet their positive preferences is more pressing. For example, patients were unanimous that staff should help them

to maintain their self-care skills, and although all staff were in favour, it appeared that this occurred in only a minority of wards.

The observed mismatches between actual ward practice and the views of patients and staff create a challenge to be addressed by management.

The results of the study have been discussed with management and changes in ward practice are planned. A follow-up study is proposed to evaluate the effects of management intervention, thereby closing the audit cycle (Smith, 1990).

## SUMMARY OF FINDINGS

- (1) The attachment of a state-enrolled nurse with specific responsibility for the elderly enabled a primary care team to become aware of the existence of elderly patients with dementia whom the team might not otherwise have been aware of.
- (2) In a small group of carers to the demented elderly, carers' knowledge about dementia was poor. Carers' perceived unmet needs for services were only modest.
- (3) Over and above routine clinical practice, structured support to carers of the demented elderly was required to improve carers' knowledge about dementia and reduce psychological morbidity.
- (4) Such support did not open the floodgates of demand for services; indeed, perceived needs were significantly reduced, without increased resource use.
- (5) Patients attending a geriatric day hospital had poor knowledge about services especially private and respite services. Unmet needs were mainly for social services. Support from general practitioners and social workers were perceived as least beneficial of services received.
- (6) There appeared to be poor matching of resources to need, based on functional status of day hospital patients.

- (7) Carers of patients admitted to a geriatric assessment unit had a high level of perceived unmet needs for long-term care services, mainly for health services, and a high proportion predicted a need for long-term institutional care placement.
- (8) The level of prior community support and carers' perceptions of its adequacy were not associated with whether elderly patients required institutionalisation following admission to acute hospital care.
- (9) Although carers overestimated the proportion of patients who required institutional care, their predictions were still associated with outcome at a high level of statistical significance.
- (10) Increased patient-carer proximity prior to institutionalisation was positively correlated with improved life-satisfaction of carers following institutionalisation of patients.
- (11) A high prevalence of cognitive impairment in elderly patients in private nursing homes and long-term geriatric and psychogeriatric hospital wards limits the value of patient self-report measures of quality of care and quality of life.
- (12) In a small population of cognitively-intact patients in private nursing homes and long-term geriatric wards, patients expressed greater dissatisfaction with care from hospital staff.

- (13) Nursing staff morale was higher in nursing homes than long-term geriatric and psychogeriatric wards.
- (14) Nursing home care for state-supported patients was cheaper than hospital care.
- (15) Nursing home patients were less dependent than hospital patients.
- (16) Overlap of dependency between geriatric and psychogeriatric patients suggests the need to rethink the separation of administrative responsibility in long-term hospital care of the elderly.
- (17) Regime and environment factors (conducive to a high quality of life in institutional care) showed high internal variation and overlap between nursing homes and hospital wards.
- (18) Patients had lower expectations than staff about regime and environment in long-term hospital care.
- (19) There was scope to improve regime and environment in long-term hospital care in line with preferences of staff and cognitively-intact patients, based on current practice in some wards.



## GENERAL DISCUSSION

### Introduction

The general aims of the thesis were to address 4 questions:

- Q1. How do consumers view long-term care services?
- Q2. How can long-term care services be evaluated from a consumer perspective?
- Q3. How can a more consumer-oriented approach to long-term care service delivery be achieved?
- Q4. What might be the resource implications of a more consumer-oriented approach to service delivery?

This section addresses how far the studies have answered these general aims, the implications for practice, and suggestions for future research.

- Q1. How do consumers view long-term care services?

In the studies, consumers' knowledge about service availability was poor. This finding is consistent with previous research (Ritchie et al, 1981). Patients' and carers' knowledge about long-term care services needs to be improved. As there has been relatively little research in this area, further studies would be valuable as consumer knowledge about services may vary according to educational and cultural factors. Research will also be required to determine the most effective methods of improving knowledge and of the benefits of improving knowledge (Gilleard, 1990).

Perceived unmet need for services is likely to be closely related to knowledge of services, but may also be an indicator of how well consumers feel supported. In the dementia carers study, it was shown that perceived needs were dramatically reduced without increasing resource use. This was accompanied by increased knowledge about services and decreased psychological morbidity. Several factors could be interacting but it does appear that counselling, including the provision of information, provides a mechanism for reducing perceived needs for support from services. Following counselling, a residue of unmet need for services will remain. The studies suggest that these will relate mainly to social services. Attention should be given to meeting these needs. Social workers could make a great impact on the quality of life of the elderly and their carers by counselling clients, providing information about services, and acting as referring agents for social services.

Social workers should be aware that consumers are a heterogeneous group, so a variety of approaches will be required to meet their needs. In all the studies where perceived unmet needs were recorded no service was perceived as needed by a majority of consumers. Therefore any interventions which rely heavily or exclusively on one form of support, even those which are widely advocated such as the provision of respite to carers (Bader, 1985; Jones and Vetter, 1985; Arie, 1986), might have only a marginal impact. A better approach would be sensitive to individual expressions of need, and given the modest levels of perceived need, packages of care tailored to individual need could be provided with reasonable budget limits. Such an approach would fit the case-management model used in the Kent

community care experiments (Davies & Challis, 1986).

In the preferences study in long-term hospital care, patients were undemanding in their preferences for aspects of regime and environment. In this situation, again, measurement of perceptions of need could be used either as a tool for planning care or as an indicator of how well care is provided, or both. Comparison with staff perceptions suggests that patients may underestimate the need for improvement so that patients' views may have to be supplemented by those of staff and relatives. However, as a starting point, patients' views should carry most weight if consumer choice is to be promoted in institutional care (National Institute for Social Work, 1988). Measurement of patient views would be a valuable addition to methods of quality assurance in institutional care which has been an elusive objective in long-term care (Kane, 1987b).

As there has been very little research to document patients' views of institutional care, it should be a priority to undertake further descriptive research in this area in order to obtain a general picture of the specific aspects of regime and environment in long-term institutional care which require most attention.

Although it may be difficult to elicit views from those who are cognitively impaired, and mechanisms for protecting their interest are required, this should not be used as an excuse to fail to elicit the views of those who can express their preferences. Lack of knowledge about the views of the institutionalised elderly is a sad reflection on

policy and practice in long-term institutional care. Consumer preferences in this context should be central to the further development of services, and should have a high priority for research funding.

Q2. How can long-term care services be evaluated from a consumer perspective?

It has already been stated that measures of consumer knowledge of services and perceived unmet needs could be useful for consumer-oriented evaluation of services. In addition, measures of perceived benefit or satisfaction with services could be useful, but there are objections to consumer evaluation of service benefit on the basis of inadequate validity of measures and lack of sensitivity (Lebow, 1982). These criticisms apply particularly to global measures of satisfaction or dissatisfaction. Where more specific aspects of services are evaluated, consumers appear to be able to discriminate (Salvage et al, 1988).

In the studies reported here, structured questionnaires were used to measure consumer satisfaction with specific services or aspects of service delivery. Patients in hospital were more dissatisfied with nursing staff than were patients in nursing homes. Patients attending a day hospital perceived greater benefit from therapists than from social workers or general practitioners. Patients in long-term hospital care were able to discriminate in their preferences for aspects of regime and environment.

Measures of satisfaction with services could be of greatest use for evaluation of the effects of change in service delivery. For example, if health authorities plan to divest responsibility for long-term hospital care for the elderly to private groups, measurement of change of patient satisfaction with care should be an important part of evaluation of the effects of the change. Ideally, this would be undertaken as a controlled experiment, but in reality is likely to occur without such formal evaluation (Impallomeni and Nicholl, 1990).

Secondly, if responsibility for community care is to shift from health to social services with the development of case management systems, it would be useful to know if patients are pleased with new packages of care.

The likelihood that there will be diversity of practice gives great scope for research to compare different approaches (Ashley-Miller, 1990). Consumer satisfaction should be an important component of such evaluation.

Another approach to evaluation of services from a consumer perspective is to measure changes in quality of life, but it must be clear which aspects of quality of life are measured and instruments need to be tailored to the precise circumstances of intended application (Kane & Kane, 1981). Indeed, as Willcocks et al (1987) suggest, a multidimensional approach to measurement of quality of life is preferable to the use of a single instrument.

Multidimensional evaluation was used in the comparative study of institutional care which allowed separate evaluation of different aspects of life in institutional care, including privacy, choice, engagement, safety, homeliness, morale, and satisfaction with staff. This approach seems particularly suited to evaluation of quality of life in institutional care, where global measures of life satisfaction have limited utility due to the high prevalence of cognitive impairment of patients in hospital and nursing home settings.

It has been argued that there is a need to change emphasis in the planning and provision of long-term care services towards measurement of the outcomes of care (Day & Klein, 1988). Careful choice and use of quality of life instruments could achieve this end.

Q3. How can a more consumer-oriented approach to long-term care service delivery be achieved?

For a more consumer-oriented approach to long-term care service delivery to be achieved, there will need to be commitment to change from general practitioners, social workers, nursing home and long-term hospital care staff.

An audit cycle approach with standards chosen by local practitioners is a useful approach in order to overcome resistance to change (Smith, 1990).

Standards developed in the thesis for audit of long-term care services include: consumer knowledge of services, perceived unmet needs for services, satisfaction with services, change in life satisfaction of carers, measures of regime and environment in institutional care, patient preferences for regime and environment, patient satisfaction with staff and patient morale. Common to all these measures is that they shift emphasis towards consumer-oriented outcomes. A full audit cycle was only completed in the primary care study. Encouragingly, the consumer-oriented approach to service delivery achieved beneficial outcomes in that study.

The standards developed in the thesis could be applied either for local internal audit or as part of a more general information system for quality assurance in long-term care. In order to facilitate use of such measures in long-term care, adequate systems for data recording in clinical practice are required. Information technology in health care is in its infancy, but is likely to expand rapidly (Black, 1989). It has been stated that computers are good servants but bad masters, so professionals should lead the development of the technology to suit the needs for information (de Dombal, 1989). There is a great opportunity at present to influence the development of information technology in order that there can be a consumer-oriented approach to evaluation of long-term care services.

The more widespread use of audit may provide the mechanism for disseminating high standards of practice based on examples of excellence (Horrocks, 1990).

In order to achieve a more consumer-oriented approach to long-term service delivery by the use of audit, front-line staff will need to be encouraged to set outcome-based standards of practice, and be supported by an information system which provides feedback about the outcomes of care. At this early stage in the development of information systems well-funded demonstration projects will be required. This may slow-down the pace of change but an evolutionary approach will be essential if the introduction of audit and information technology are to be successfully implemented (Nixon, 1990).

It has been shown in this thesis that it is possible to set standards and improve practice in long-term care. Further research is required to determine whether improvement in practice can be maintained in the longer term using an audit cycle approach.

Q4. What might be the resource implications of a more consumer-oriented approach to long-term care service delivery?

A matter of growing concern in long-term care will be to balance the objectives of developing a more consumer-oriented approach while maintaining a system for equitable distribution of limited resources. It could be argued that consumer demand is potentially infinite



(Cooper, 1975). Meeting the perceived needs of one consumer may reduce the capability to meet the perceived needs of another.

However, in the dementia carers study it was demonstrated that perceived needs could be reduced without increasing resource use. How well carers felt they were supported appeared to be important. Furthermore, evidence from the dementia carers study, the day hospital perceptions study and the preferences in institutional care study all support the impression that consumer perceived needs for resources are modest in stable situations. This may be a cohort effect unique to a generation of elderly and their carers who have been brought up with low expectations for state support and future cohorts might have higher expectations. Nevertheless, it is quite clear that the case has yet to be made that there would be higher demands for resources if consumers are encouraged to become more involved in the planning and provision of services.

It is central government policy to provide long-term care for the elderly in the community on the basis that it is thought that the elderly prefer to stay in their own homes for as long as possible (Department of Health and Social Security, 1981). However, community care may be more expensive for some patients than institutional care (Spoor, 1986; Wager, 1972; Kendall, 1989), especially if opportunity costs for informal carers are included (Hu et al, 1986; Wright et al, 1981; Wright, 1987). Longitudinal studies are required to evaluate the economic consequences of institutionalisation as well as its effects on the quality of life of patients and carers. Adequate follow-up will be required to describe immediate and long-term effects.

Although expensive, such studies should be funded in order to underpin rational long-term care policy and planning.

There is concern about the escalating cost of private nursing home care, particularly for less disabled patients who might not need care (Primrose, 1988). However, the comparative study of institutional care suggests that long-term care in geriatric wards may be more expensive than private nursing home care for state-supported patients.

The relationship between cost and quality in long-term care is complex, but amenable to economic analysis (Fordyce et al, 1981). Patient disability is related to the cost of care (Holahan et al, 1983; McKechnie et al, 1982), but even when disability was taken into account, Darton and Knapp (1984) found no relationship between the cost of providing care and its quality. In the institutional care comparative study, it appeared that there was no simple relationship between quality of care and cost or disability of patients. It may be possible, therefore, to achieve a more consumer oriented approach to institutional care service delivery independent of the cost of care or disability of patients.

Alternatively, experience in the United States (Kane et al, 1983a, b) has shown that it is possible to predict outcome of nursing home care on the basis of patients' medical, functional, psychological and social status, and it is therefore feasible to reward homes which achieve better than expected outcomes (Kane, 1987). Such a model could be used in the United Kingdom to regulate quality of care for state-funded patients whose care is provided by the private sector,

and the standards for long-term care developed in this thesis could form part of the basis for measuring outcome.

Much research activity will be required to determine the predictors of high quality care. A considerable amount of work will be required to determine the relationship between case-mix (medical, functional, psychological and social status of patients) and outcome.

A shift in long-term care service delivery towards a consumer perspective could do much to improve the quality of life of the dependent elderly and their carers (Wells & Freer, 1988). Limited evidence in this thesis suggests that a consumer-oriented approach is compatible with economy of resource utilisation. However, the resource implications of a long-term shift towards consumerism are not clear. It is therefore vital that evaluative research of developments in long-term care service delivery should include an economic appraisal.

### Incidental Findings

Other findings in the thesis raised issues which require general discussion.

1. Under the new General Practitioner contract, general practitioners are obliged to undertake annual checks on the elderly. For there to be any benefit to accrue from this considerable undertaking, action must follow identification of problems (MacLennan, 1990).

In the study of primary care support for carers of the demented elderly, there was a gap between identification of the demented elderly (as far as could be judged the demented elderly with symptoms were known to the team) and action (there was a need to improve support to carers). Careful attention must be given to ensure that information is not simply held within a primary care team, but a concentration of effort should be applied to making use of information to the benefit of patients. A similar argument applies to social work case-management. For there to be benefit to patients, action must follow identification of problems.

2. The low prevalence of symptomatic dementia found in the primary care study, which is consistent with other recent community studies (Clarke et al, 1986; Lindesay et al, 1989) suggests that workload generated for primary care teams by detection of dementia in the elderly living at home need not be excessive, amounting to an average of only about 4 cases per general practitioner. However, screening for cognitive impairment could yield a high proportion of borderline cases, and choice of the cut-off point on a screening instrument may be crucial. A low threshold for detection (e.g.  $\leq 10/13$  on a screening instrument (Jachuck et al, 1986) used in the study reported here) would identify many cases of cognitive impairment (33% of the population aged >75 in the study in the study) and considerable workload would be generated to confirm or refute a diagnosis of dementia in this group. In addition, anxiety in identified subjects and their carers could be induced and even if early dementia is confirmed, this may have harmful effects on how carers perceive the elderly person (Pollitt et al, 1989).

3. There is considerable interest in who should provide long-term institutional care for the elderly (MacLennan, 1988a). In the comparative study of institutional care, evidence of overlap of dependency of geriatric and psychogeriatric patients suggests that the separation of administration of care for these groups is inappropriate. Even if patients can be separated on entry to each institution on the basis of dependency, they cannot be easily separated in a cross-sectional survey of patients who have been in care for some time. Swapping patients between institutions as dependency changes would be inhuman and probably dangerous in view of reports of relocation mortality (Grey, 1978). A more ethical approach, and one which might better meet the needs of patients and staff, would be to provide separate care for the small group of patients who are cognitively-intact and for the group with severe behavioural disturbance. Staff could be specifically trained to meet the needs of these groups as well as those who are cognitively-impaired but not behaviourally disturbed. A common administrative structure with input from geriatrics and psychogeriatrics should be able to provide this service for a local population. Even if institutional care for the frail elderly were to shift further towards care provided by private nursing homes, sufficient influence could be brought to bear by social work departments, local geriatricians, psychogeriatricians and general practitioners to ensure that such arrangements could apply to the private nursing homes.

Some might argue against separate care facilities for different groups on the basis of experience in residential care (Meacher, 1972) but this argument carries less weight for care of the more frail elderly. While

it may be feasible to integrate up to 30% of confused with cognitively-intact elderly in residential care (Wilkin et al, 1982) it could be against the interests of the handful of cognitively-intact elderly or the severely disturbed elderly to integrate them into a ward or home where practice is oriented towards the vast majority of confused but not disturbed elderly who live in long-term hospital wards and nursing homes.

4. It was proposed that local authorities should act as purchasers rather than providers of long-term services (Griffiths, 1988). This gives them an independent perspective from which to select services on the basis of quality and cost.

It is perhaps unfortunate that the original proposals were amended in two respects (Secretaries of State for Health, Social Security, Wales and Scotland, 1989). First, as budgets for community care will not be ring-fenced, there may be greater pressure on local authorities to opt for the cheapest options without reference to quality of care or preferences of clients (Beardshaw, 1990). Second, many health authorities are likely to retain responsibility for providing long-term institutional care for geriatric and psychogeriatric populations. Clear delineation of responsibility for different groups of patients could be fudged and lead to professional dispute about responsibilities. Perverse incentives to move patients for financial reasons will remain and will also continue to impede joint-planning between health and social services.

## CONCLUSIONS

The studies in the thesis support the view that consumers of long-term care services lack information about services. Consumer demand appears to be modest, but consumers have specific needs, both in the community and in institutional care.

Evaluation of long-term care services from a consumer perspective is possible using a variety of approaches, including measurement of consumer satisfaction, knowledge, unmet needs, psychological morbidity, life satisfaction and quality of life indices which do not rely on patient self-report measures. There is considerable scope to improve care even in areas which are often regarded as offering little scope for improvement, such as in community care for the demented elderly, and in long-term hospital care.

The more widespread use of consumer-oriented standards in long-term care provides a mechanism for achieving higher quality of care and quality of life for consumers.

There is no evidence to suggest that a consumer-oriented approach will be more expensive than current practice, although evaluation of long-term effects of change in practice will need to include an economic appraisal.

"An aged man is but a paltry thing,  
A tattered coat upon a stick, unless  
Soul clap its hands and sing, and louder sing <sup>1</sup>  
For every tatter in its mortal dress"

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<sup>1</sup>W.B. Yeats (1865-1939)  
Quotation from "Sailing to Byzantium".



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Psychosocial predictors of mortality among the elderly poor: The role of religion, well-being and social contacts.  
American Journal of Epidemiology 119, 410-423.



### Publications

The following reports of work undertaken in the thesis have been published.

1. Philp I, Young J (1988)  
Audit of support given to lay carers of the demented elderly by a primary care team.  
Journal of the Royal College of General Practitioners 38(309), 153-155.
2. Philp I, Young J, Pollock M (1988)  
An audit of a primary care team's knowledge of the existence of symptomatic demented elderly.  
Health Bulletin 46(2), 93-97.
3. Philp I (1988)  
Meeting the needs of demented patients and their carers.  
Geriatric Medicine 18(11), 73-80.  
(Overall winner of Insight Award for Improving Care of the Elderly).
4. Philp I, Mutch WJ, Ogston S, Devaney J (1989)  
Can quality of life of old people in institutional care be measured.  
Journal of Clinical and Experimental Gerontology 11(1/2), 11-21.
5. Philp I, Mutch WJ, Ballinger B, Boyd L.  
A comparison of care in private nursing homes, geriatric and psycho-geriatric hospital wards.  
International Journal of Geriatric Psychiatry (in press).

APPENDICES

Primary Care Study

ALVA MEDICAL PRACTICE

Health Centre  
Alva

Dear

I am a general practitioner trainee working in the Alva practice. As part of my training I am undertaking a research project into memory of the elderly. This will involve your Health Visitor calling to ask a few simple questions. Following her visit I may call. I will not be carrying out a physical examination during my visit.

If, however, you do not wish to participate we would be grateful if you would let us know by signing the bottom of this letter and returning it to us, in which case we will not trouble you further.

Mrs                      will call on                      to see you.

Thank you in anticipation for your help and I look forward to meeting you.

Yours sincerely,

I. Philp

---

To Alva Medical Practice

I do not wish to participate in your project. Please do not call.

Signed.....

APPENDIX 1(a)

Name ..... Y.O.B. ....  
 Address..... Sex: M or F  
 .....

B.P. ....

Mental Impairment assessment: Mild or Mod or Severe

<u>MTS Evaluation</u>	<u>Score</u>
1. Age to one year	0 1
2. Time to nearest hour	0 1
3. Address to recall: 95 High Street	0 1 2
4. Date	0 1 2 3
5. Day of week	0 1
6. Address of GP's surgery	0 1
7. Date of birth	0 1
8. Year of First World War	0 1
9. Name of present monarch	0 1
10. Count backwards 20 - 1	0 1

---

Total Score

---

QUESTIONNAIRE

Name of Patient \_\_\_\_\_

Address \_\_\_\_\_

D.O.B. \_\_\_\_\_

Name of Carer \_\_\_\_\_

Relationship of Carer to Patient \_\_\_\_\_

Duration of Symptoms \_\_\_\_\_

Mental Test Score \_\_\_\_\_

Previously known to G.P. Team \_\_\_\_\_ Yes / No \_\_\_\_\_

Known to Psychogeriatrician \_\_\_\_\_ Yes / No \_\_\_\_\_

Contact between Carer and Patient \_\_\_\_\_

Night and Day \_\_\_\_\_

Day only (specify) \_\_\_\_\_

APPENDIX 1(a)

What do you know about dementia?

Please indicate whether you have been told the following about dementia and by whom.

	Yes/No	By whom
1) Memory loss may occur		
2) Personality may become less inhibited		
3) There may be wandering		
4) There may be apathy		
5) There may be aggressiveness		
6) Incontinence may occur		
7) There is a need for increased safety at home and precautions need to be taken		
8) There are two main forms of dementia		
9) Dementia usually progresses		
10) There is no cure at present		
11) Relatives can do a lot to help		
12) Financial help is available		
13) Social services are available		
14) Nursing services are available		
15) Hospital services are available		

APPENDIX 1(a)

The following is a list of services which may be available to patients with dementia and their carers.

In Column (A): Tick those which you are receiving

In Column (B): Tick those which you are not receiving, but which you think may be of help.

Of these, indicate in Columns 3 - 5 why you are not receiving them.

In Column (C): Tick if you have never heard of these services.

In Column (D): Tick if you have been told about these services, but it is not available or you are on the waiting list.

In Column (E): Tick if services are not accepted by the patient. Indicate why.

APPENDIX 1(a)

	A	B	C	D	E
Day Hospital					
Respite Admission					
Long term institutional care					
Community nursing services					
Home help					
Meals on wheels					
Day centre					
Social worker					
Laundry service					
Incontinence service					
Attendance allowance					
Invalid care allowance					
Additional supplementary benefits					
Luncheon club					
Alzheimer's Society					
Relative support group					
Crossroads					
Others (specify)					



SERVICES

- A. Which services do you know?  
 B. Which services do you get?  
 C. Which services would you like? (please tick)

A            B            C  
 Know      Get      Would like  
 (within last month)

(i) Domiciliary and Community Services

01	Home Help	<input type="checkbox"/>	01	<input type="checkbox"/>	01	<input type="checkbox"/>
02	Night sitter	<input type="checkbox"/>	02	<input type="checkbox"/>	02	<input type="checkbox"/>
03	Private help	<input type="checkbox"/>	03	<input type="checkbox"/>	03	<input type="checkbox"/>
04	Private nursing	<input type="checkbox"/>	04	<input type="checkbox"/>	04	<input type="checkbox"/>
05	Minister/Priest	<input type="checkbox"/>	05	<input type="checkbox"/>	05	<input type="checkbox"/>
06	Crossroads	<input type="checkbox"/>	06	<input type="checkbox"/>	06	<input type="checkbox"/>
07	Other voluntary involvement	<input type="checkbox"/>	07	<input type="checkbox"/>	07	<input type="checkbox"/>
08	Relative support group	<input type="checkbox"/>	08	<input type="checkbox"/>	08	<input type="checkbox"/>
09	Social worker	<input type="checkbox"/>	09	<input type="checkbox"/>	09	<input type="checkbox"/>
10	Laundry service	<input type="checkbox"/>	10	<input type="checkbox"/>	10	<input type="checkbox"/>
11	Occupational therapy	<input type="checkbox"/>	11	<input type="checkbox"/>	11	<input type="checkbox"/>
12	Physiotherapy	<input type="checkbox"/>	12	<input type="checkbox"/>	12	<input type="checkbox"/>
13	Day centre	<input type="checkbox"/>	13	<input type="checkbox"/>	13	<input type="checkbox"/>
14	Luncheon club	<input type="checkbox"/>	14	<input type="checkbox"/>	14	<input type="checkbox"/>
15	Meals on wheels	<input type="checkbox"/>	15	<input type="checkbox"/>	15	<input type="checkbox"/>
16	Social club/outings	<input type="checkbox"/>	16	<input type="checkbox"/>	16	<input type="checkbox"/>
17	Private nursing home/long term care	<input type="checkbox"/>	17	<input type="checkbox"/>	17	<input type="checkbox"/>
18	Residential home/long term care	<input type="checkbox"/>	18	<input type="checkbox"/>	18	<input type="checkbox"/>
19	Sheltered housing	<input type="checkbox"/>	19	<input type="checkbox"/>	19	<input type="checkbox"/>
20	Other (specify)	<input type="checkbox"/>	20	<input type="checkbox"/>	20	<input type="checkbox"/>

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21	Other (specify)	<input type="checkbox"/>	21	<input type="checkbox"/>	21	<input type="checkbox"/>
----	-----------------	--------------------------	----	--------------------------	----	--------------------------

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(ii) Health Services

22	General practitioner	<input type="checkbox"/>	22	<input type="checkbox"/>	22	<input type="checkbox"/>
23	Health visitor	<input type="checkbox"/>	23	<input type="checkbox"/>	23	<input type="checkbox"/>
24	District nurse	<input type="checkbox"/>	24	<input type="checkbox"/>	24	<input type="checkbox"/>
25	Community psychiatric nurse	<input type="checkbox"/>	25	<input type="checkbox"/>	25	<input type="checkbox"/>
26	Psychiatrist	<input type="checkbox"/>	26	<input type="checkbox"/>	26	<input type="checkbox"/>
27	Psychologist	<input type="checkbox"/>	27	<input type="checkbox"/>	27	<input type="checkbox"/>
28	Day hospital - geriatric	<input type="checkbox"/>	28	<input type="checkbox"/>	28	<input type="checkbox"/>
29	Day hospital - psychogeriatric	<input type="checkbox"/>	29	<input type="checkbox"/>	29	<input type="checkbox"/>
30	Geriatric hospital respite admission (within last year)	<input type="checkbox"/>	30	<input type="checkbox"/>	30	<input type="checkbox"/>
31	Psychogeriatric hospital respite admission (within last year)	<input type="checkbox"/>	31	<input type="checkbox"/>	31	<input type="checkbox"/>
32	Geriatric hospital long-term care	<input type="checkbox"/>	32	<input type="checkbox"/>	32	<input type="checkbox"/>
33	Psychiatric long-term care	<input type="checkbox"/>	33	<input type="checkbox"/>	33	<input type="checkbox"/>
34	Other (specify)	<input type="checkbox"/>	34	<input type="checkbox"/>	34	<input type="checkbox"/>

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35	Other (specify)	<input type="checkbox"/>	35	<input type="checkbox"/>	35	<input type="checkbox"/>
----	-----------------	--------------------------	----	--------------------------	----	--------------------------

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DAY HOSPITAL STUDY

## Patient Details:

Name: \_\_\_\_\_

Age: \_\_\_\_\_ Sex: Male / Female MSQ: \_\_\_\_\_

Physical Functioning:

Continence:           Continent           Incontinent           Catheter

Mobility:           Free           Stick           Zimmer           Wheelchair

Dressing:           Independent    Help with shoes/buttons only    Dependent

Social Functioning:

Shopping:           Independent / Dependent

Cooking:           Independent / Dependent

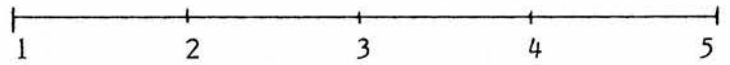
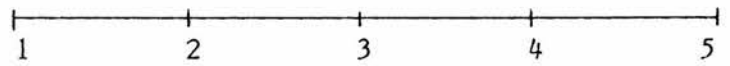
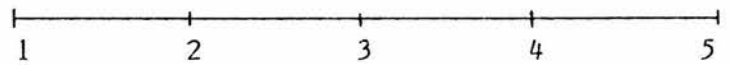
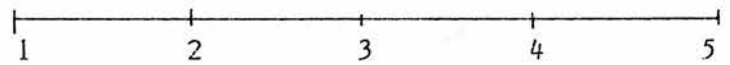
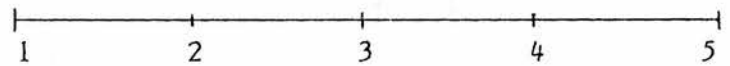
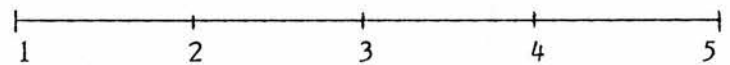
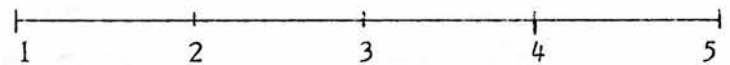
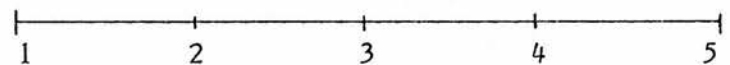
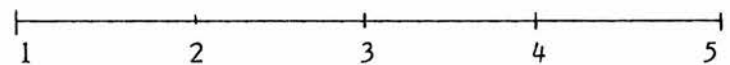
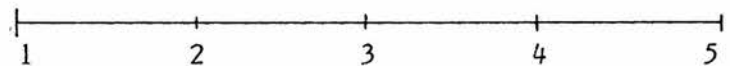
Lay Support:

Day + Night       /   Daily   /   Less than daily

Relationship:

SERVICE BENEFIT

Please circle the number which most clearly corresponds with your opinion about the benefit to you for each service you get:

Service
 

 

 

 

 

 

 

 

 

 


Code: 1 = No benefit  
 2 = Only a little benefit  
 3 = Some benefit  
 4 = A lot of benefit  
 5 = The most benefit possible

ASSESSMENT UNIT

Introduction - We are undertaking a study looking at the use of services and relatives' satisfaction with support for old people prior to hospital admission.

We would be very grateful if you could complete the questionnaire. We will explain any of the terminology which you may not understand.

GENERAL INFORMATION

Today's date: \_\_\_\_\_

Your details

1. Name: \_\_\_\_\_ 2. Age: \_\_\_\_\_  
 2. Sex: \_\_\_\_\_ 4. Marital Status: \_\_\_\_\_  
 5. Relationship to Patient: \_\_\_\_\_  
 6. Occupation: \_\_\_\_\_

Patient's details

7. Name: \_\_\_\_\_ 8. Age: \_\_\_\_\_  
 9. Sex: \_\_\_\_\_ 10. Marital Status: \_\_\_\_\_  
 11. Placement prior to admission: Home alone / Home with relative /  
 Residential Home / Private Nursing Home /  
 Other (specify): \_\_\_\_\_

To be completed by doctor in discharge:

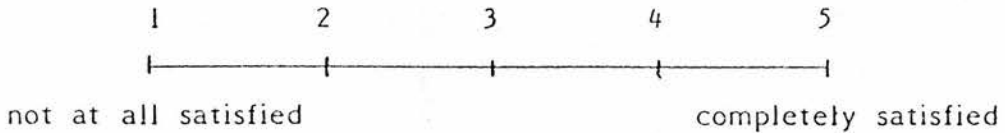
1. Date of admission: \_\_\_\_\_ 1a. MSQ on admission: \_\_\_\_\_  
 2. Date of discharge/death: \_\_\_\_\_  
 3. Placement: Home alone / Home with relative / Residential Home /  
 Private Nursing Home / Continuing Care / Died  
 4. Diagnoses on discharge: \_\_\_\_\_

SATISFACTION

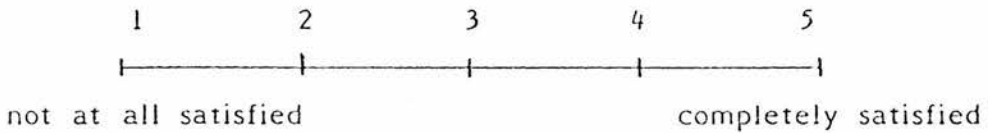
PLEASE CIRCLE THE NUMBER WHICH MOST CLOSELY CORRESPONDS WITH YOUR OPINION.

(i) Family

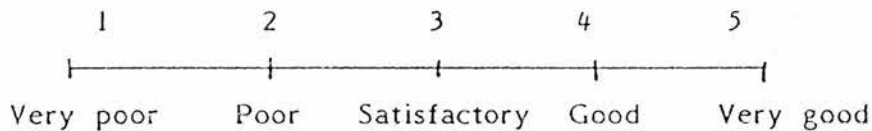
How satisfied are you with help from other family?

(ii) Professional

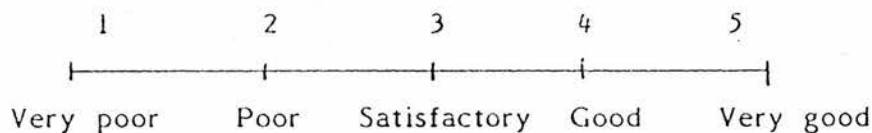
How satisfied are you with the professional help you receive

(iii) Past and present relationship

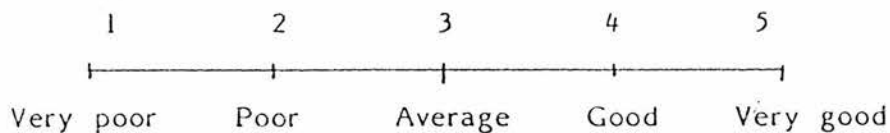
Overall, how would you rate the quality of your relationship before your relative became ill?



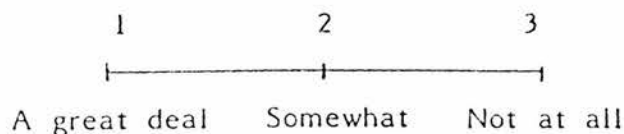
Overall, how would you rate the quality of your relationship now?

(vi) Your health

a) Over the past 12 months has your health been



b) Do you think your health has suffered because of having to care for your relative?



SUPPORT

What support did you receive prior to hospital admission (Actual)?

What support would you have liked to receive or have received more of (Desired)?

(Please tick)

(i) <u>From Family and Friends</u>	Actual (within last month)		Desired
01 Day support	<input type="checkbox"/>	01	<input type="checkbox"/>
by whom? _____			
02 Night support	<input type="checkbox"/>	02	<input type="checkbox"/>
by whom? _____			
03 Holiday respite (within last year)	<input type="checkbox"/>	03	<input type="checkbox"/>
by whom? _____			
04 Social visits	<input type="checkbox"/>	04	<input type="checkbox"/>
by whom? _____			
05 Other practical support	<input type="checkbox"/>	05	<input type="checkbox"/>
specify _____			

(ii) From Domicillary and Community Services

06 Home help	<input type="checkbox"/>	06	<input type="checkbox"/>
07 Night sitter	<input type="checkbox"/>	07	<input type="checkbox"/>
08 Private help	<input type="checkbox"/>	08	<input type="checkbox"/>
09 Private nursing	<input type="checkbox"/>	09	<input type="checkbox"/>
10 Minister/Priest	<input type="checkbox"/>	10	<input type="checkbox"/>
11 Crossroads	<input type="checkbox"/>	11	<input type="checkbox"/>
12 Other voluntary involvement	<input type="checkbox"/>	12	<input type="checkbox"/>
13 Relative support group	<input type="checkbox"/>	13	<input type="checkbox"/>
14 Social worker	<input type="checkbox"/>	14	<input type="checkbox"/>
15 Laundry service	<input type="checkbox"/>	15	<input type="checkbox"/>
16 Occupational therapy	<input type="checkbox"/>	16	<input type="checkbox"/>
17 Physiotherapy	<input type="checkbox"/>	17	<input type="checkbox"/>
18 Day centre	<input type="checkbox"/>	18	<input type="checkbox"/>
19 Luncheon club	<input type="checkbox"/>	19	<input type="checkbox"/>
20 Meals on wheels	<input type="checkbox"/>	20	<input type="checkbox"/>
21 Social club/outings	<input type="checkbox"/>	21	<input type="checkbox"/>
22 Private nursing Home/ Long term care	<input type="checkbox"/>	22	<input type="checkbox"/>
23 Residential Home/Long term care	<input type="checkbox"/>	23	<input type="checkbox"/>
24 Sheltered housing	<input type="checkbox"/>	24	<input type="checkbox"/>
25 Other (specify)	<input type="checkbox"/>	25	<input type="checkbox"/>
26 <u>Other (specify)</u> _____	<input type="checkbox"/>	26	<input type="checkbox"/>

(iii) From Health Service		Actual (within last month)	Desired	
27	General Practitioner	<input type="checkbox"/>	27	<input type="checkbox"/>
28	Health Visitor	<input type="checkbox"/>	28	<input type="checkbox"/>
29	District nurse	<input type="checkbox"/>	29	<input type="checkbox"/>
30	Community psychiatric nurse	<input type="checkbox"/>	30	<input type="checkbox"/>
31	Psychiatrist	<input type="checkbox"/>	31	<input type="checkbox"/>
32	Psychologists	<input type="checkbox"/>	32	<input type="checkbox"/>
33	Day hospital-geriatric	<input type="checkbox"/>	33	<input type="checkbox"/>
34	Day hospital-psychogeriatric	<input type="checkbox"/>	34	<input type="checkbox"/>
35	Geriatric hospital respite admission (within last year)	<input type="checkbox"/>	35	<input type="checkbox"/>
36	Psychogeriatric hospital respite admission (within last year)	<input type="checkbox"/>	36	<input type="checkbox"/>
37	Geriatric hospital long-term care	<input type="checkbox"/>	38	<input type="checkbox"/>
38	Psychiatric hospital long-term care	<input type="checkbox"/>	39	<input type="checkbox"/>
39	Other (specify)	<input type="checkbox"/>	40	<input type="checkbox"/>
40	Other (specify)	<input type="checkbox"/>	41	<input type="checkbox"/>

#### Future Care

a) What would you like to happen to your relative in the future? (please circle)

Discharge home alone / Home with relative /

Residential Home / Private nursing home /

Long-term hospital care / Other (specify) \_\_\_\_\_

Thank you very much for your help with this questionnaire.

Change in Carers' Life SatisfactionPatient's details:

Age: Sex: Male/Female

Duration in institutional care

Your details:

Age: Sex: Male/Female

Relationship to patient:

Previous support to patient:

- Lived with patient
- Daily support for patient
- At least weekly support for patient
- Less than weekly support for patient

How satisfied are you with life as a whole these days?  
All things considered, would you say you are:

- Very satisfied = 4
- Fairly satisfied = 3
- Not very satisfied = 1
- Not at all satisfied = 0
- Don't know = 2

And, before your relative was admitted to institutional care,  
how satisfied were you with your life? Would you say you were:

- Very satisfied = 4
- Fairly satisfied = 3
- Not very satisfied = 1
- Not at all satisfied = 0
- Don't know = 2



COMPARATIVE STUDY OF INSTITUTIONAL CARE

The following questionnaires have been developed for reliable measurement of different dimensions of quality of life in long-term hospital care and nursing homes.

There are three main categories of outcome:

- 1) Policy factors
- 2) Environmental factors
- 3) Patient morale

In addition, questionnaires for staff morale are included. It is recommended that patient dependency should also be measured in this context. There are several validated instruments (e.g. Wilson and Brass (1), Gilleard and Pattie (2), Katz et al (3)).

Patients with cognitive impairment should be excluded from interview for patient morale.

Each measure (e.g., choice, safety features) is independent of other measures, although some questions appear on more than one questionnaire. In some instances an answer to a question (e.g. night lights at night) gives a positive mark for one measure (safety features) and a negative mark for another (patient-oriented policies). It should be clear, therefore, that a unitary measure for overall quality of life cannot be calculated by adding together the scores for the individual measures.

References

1. Katz S, Downs TD, Cash HR, Grotz RC. Progress in development of the index of ADL. *The Gerontologist* 1970, 1, 20-30.
2. Gilleard CJ, Pattie AH. The Stockton Geriatric Rating Scale. A shortened version with British normative data. *British Journal of Psychiatry* 1977, 131, 90-94.
3. Wilson LA, Brass W. Brief assessment of the mental state in geriatric domiciliary practice. The usefulness of the mental status questionnaire. *Age and Ageing* 1973, 2, 92-101.

REGIME

## Choice

Source: Interview with charge nurse

Score: Multiply by 100/11

Do patients have their own cabinets in which they can lock up their personal possessions?	Yes = 1
Is there a fairly set time at which patients are awakened in the morning?	No = 1
Is there a fairly set time at which patients are expected to go to bed at night?	No = 1
Can patients choose when they have their full breakfast..	every day? = 2 some days? = 1
Can patients use their bedroom areas..	Whenever they want? = 1
Are patients encouraged to bring their own furniture?	Yes = 1
Is there somewhere patients can make a cup of tea or coffee?	Yes = 1
Is there a telephone available for patients' use?	Yes = 1
If assisted, can patients come and go outside the ward..	Whenever they wish? = 1
Can visitors come..	At any time? = 1
	Total = 11

REGIME

## Privacy

Source: Interview with charge nurse

Score: Multiply by 20

Do patients have privacy whenever they want? Yes = 1

Do patients generally have privacy for entertaining their visitors? Yes = 1

Is there somewhere patients can make phone calls in private (apart from main office)? Yes = 1

Do patients always have the same person to assist them at bathtime? Same person = 1

Can patients lock their own rooms? Yes = 1

Total = 5

REGIME

## Involvement

Source: Interview with charge nurse

Score: Multiply by 20

Do patients have a say in the general organisation of this ward?	Yes = 1
Do patients set up their own activities?	Yes = 1
Are patients involved in planning menus other than choosing from a list?	Yes = 1
Is there a handbook available for new or prospective patients telling them how the individual ward is run?	Yes = 1
Is there a patients' committee held..	At least once a month = 1
	Total = 5

REGIME

## Engagement

Source: Interview with charge nurse

Score: Multiply by 100/7

Do patients get individual attention?	Yes = 1
Do staff members sometimes do things for patients that they could do themselves?	No = 1
Are patients taught new skills?	Yes = 1
Are patients encouraged to maintain their self-care skills?	Yes = 1
Do a lot of patients just seem to be passing time here?	No = 1
Do staff encourage patients to help themselves a lot, a little, or not at all?	A lot = 1
Are staff encouraged to sit and talk with patients as part of their job?	A lot = 1 ✓
	Total = 7

REGIME

## Patient-orientated policies

Source: Interview with charge nurse

Score: Multiply by 100/17

There are both smoking and smoke-free rooms	= 1
There are some separate and some mixed WCs	= 1
Staff use patients WCs	= 1
There are emergency unlocking arrangements for patients use	= 1
There is a notice board	= 1
Night lights are used only when necessary	= 1
Patients can change the layout of their bed area	= 1
Patients can bring their own furniture	= 1
There are facilities in patients bed areas for locking away possessions	= 1
Patients can change the decor of their bed area	= 1 ✓
The ward has a patients committee	= 1
Commodes are used only when necessary	= 1
Patients are taught new skills	= 1
Patients can plan their own entertainments and events	= 1
Patients can design their own menus, over and above choosing from a list	= 1
Patients can get up when they wish	= 1
Patients can go to bed when they wish	= 1

Total = 17

REGIME

## Staff-orientated policies

Source: Interview with charge nurse

Score: Multiply by 100/12

Separate WC for the staff	= 1
Night lights are always on at night	= 1
Commodos are used automatically	= 1
Patients have no say in the running of the ward	= 1
Patients are not taught any new skills	= 1
Patients do not organise their own activities	= 1
Patients do not organise their own entertainment	= 1
The planning of menus does not involve the patients other than choosing from a list	= 1
A handbook is not produced for each ward	= 1
Patients get up at a set time	= 1
Patients go to bed at a set time	= 1 ✓
There are day attenders	= 1
Total	= 12

## ENVIRONMENT

## Physical amenities

Source: Ward inspection  
 Score: Multiply by 100/19

If supplementary heating in..  
 (score up to 1 if only one lounge)

All lounges =2  
 Some lounges =1

If there is a WC within 10m of..  
 (score up to 1 if only one lounge)

All lounges =2  
 Some lounges =1

If there is a WC within 10m of..  
 (score 0 if no separate dinning-room)

All dinning-rooms =2  
 Some dinning-rooms =1

If one bath for fifteen patients or fewer

=1

If one WC for four patients or fewer

=1

If all WCs have doors

=1

If there is a separate sluice room

=1

If there is a laundry

=1

If there is an ironing/sewing room

=1

If there is access to..

Patients' phone =2  
 Staff phone =1

If bedside lights are provided for and can be used by  
 all patients

All patients =2  
 Some patients =1

If bed areas have socket outlets which patients can  
 use..

All bed areas =2  
 Some bed areas =1

If patients' rooms can be used as bedsitting rooms  
 (Score 0 if less than 50% of patients have their  
 own rooms)

=1

Total = 19



## ENVIRONMENT

## Socio-recreational

Source: Ward inspection  
 Score: Multiply by 12.5

View of street/garden or street/sea (i.e. interesting location) from lounge areas	= 1
If there is more than one television	= 1
If there is a recreation room for hobbies/handicrafts plus bar	= 1
If there is a quiet room	= 1
If there is a visitors' room	= 1
If there is a garden for patients to sit in	= 1
If it is easy for mobile patients to get into the garden unaided	= 1 ✓
If there are chairs in the main entrance hall	= 1
Total	= 8

## ENVIRONMENT

## Prosthetic aids

Source: Ward inspection

Score: Multiply by 100/14

If there are handrails in..	All lounge areas	=2
	Some lounge areas	=1

If there are handrails in..	All dining areas	=2
	Some dining areas	=1

If one or more WCs are adapted for use by patients in wheelchairs	=1
---	----

If one or more WCs are raised on platforms to assist patients who have trouble using WCs of normal height or if portable seat available	=1
---	----

If WCs have handrails or grips	In all WCs =2
--------------------------------	---------------

If corridors appear light or are artificially lit	=1
---	----

If there are no steps or ramps, etc. in the corridors	=1
---	----

If handrails in the main corridor are	Continuous	=2
	In sections	=1

*If there is a lift in the ward	=1
---------------------------------	----

*If the lift can accommodate a wheelchair	=1
---	----

Total = 14

(\*Note: If ward is ground floor score 1 for both of these items)

## ENVIRONMENT

## Orientational aids

Source: Ward inspection

Score: Multiply by 20

If there is a patients' noticeboard	=1
If any rooms are identified by signs	=1
If any routes are identified by signs	=1
If any rooms are identified by colour coding	=1
If any routes are identified by colour coding	=1
Total	= 5

## ENVIRONMENT

## Safety features

Source: Ward inspection  
 Score: Multiply by 100/14

If there are emergency unlocking arrangements for staff use in bathroom and WCs		= 1
If there is a call system..	In bathrooms	= 1
	In WCs	= 1
If there is a night light kept on at night in patient bed areas..	In all	= 2
	In some	= 1
If there is a call system in patients' bed areas		= 1
If it can be reached by patients..	All	= 2
	Some	= 1
If the corridors are lit at night		= 1
If there are fire doors along the corridors		= 1
If there are smoke/heat detectors in corridors		= 1
If there is emergency lighting		= 1
If the bed areas contain fitted furniture..	All bed areas	= 2
	Some bed areas	= 1
	Total	= 14

## ENVIRONMENT

## Architectural choice

Source: Ward inspection

Score: Multiply by 5

If windows can be opened by the patients in.. (score up to 1 if only 1 lounge)	All lounge areas =2 Some lounge areas =1
If there is a lounge with no TV	=1
If windows can be opened by patients in.. (score 0 if no separate dining room)	All dining areas =2 Some dining areas =1
If there is a mixture of large and small tables in the dining area	=1
If the ward has two of the following - ambulift, medibath, ordinary bath with grips	=1
^If there is a separate shower room in the ward	=1
If there is/are shower(s) in the bathroom(s)	=1
If there are separate WCs for men and women (Score 0 if single sex ward)	=1
If there is a patients' shop	=1
If there is a patients' tea-making room	=1
If there is a chiropody/hairdressing room	=1
If more than 50 per cent of patients have single bedrooms	= 1
If patients can control the heating in their bed areas	=1
If patients can open the windows in their bed areas	=1
If bed areas contain wash-hand basins	In all =2 In some =1
If there are locks on bathrooms/WCs	=1
If there is somewhere of their own for patients to lock away personal possessions	=1
	Total = 20

## ENVIRONMENT

## Space availability

Source: Ward inspection

Score: Multiply by 100/3

If sitting/dining space per patient equal to or greater than  $5.4\text{m}^2$  ( $7\frac{1}{2} \times 7\frac{1}{2}$  feet) = 1

If size of single bed area equal to or greater than  $10\text{m}^2$  ( $10\frac{1}{2} \times 10\frac{1}{2}$  feet) = 1

If size of double bed area equal or greater than  $15.5\text{m}^2$  (13 x 13 feet) = 1

Total = 3

## ENVIRONMENT

## Staff facilities

Source: Ward inspection  
Score: Multiply by 100/7

If staff use their own WC and not the patients	= 1
If there is an office	= 1
If there is an additional staff common room/locker room/ cloakroom	= 1
If there is an additional medical/clinic/doctor's room	= 1
If there is an additional duty room	= 1
If there is a staff house on site	= 1
If there is a staff flat/maisonette on site	= 1
Total	= 7

## PATIENT-MORALE

## Patient's worries

Source: Interview with patient

Score: Multiply by 12.5

Now during the past few weeks have you been worried about any of the following . . .

1. Worried about not having enough money for extras	Yes No	= 1 = 0
2. Worried about your family	Yes No	= 1 = 0
3. Worried about people you have trouble with in the ward	Yes No	= 1 = 0
4. Worried about your health	Yes No	= 1 = 0
5. Worried about having a fall	Yes No	= 1 = 0
6. Worried about the way the ward is run	Yes No	= 1 = 0
7. Worried about the safety of your possessions in the ward	Yes No	= 1 = 0
8. Worried about being safe if there was a fire	Yes No	= 1 = 0
	Total	= 8

## Worries about ward

Source: Factor analysis of above

Score: Multiply items 3 and 6 by 50



## PATIENT-MORALE

## Change in life satisfaction since coming to ward

Source: Interview with patient

Score:  $(A + B + 4) \times 12.5$ 

This gives a value of 0-100. Values higher than 50 indicate a drop in life satisfaction since admission.

A. How satisfied are you with your life as a whole these days? All things considered would you say you are

Very satisfied	-4
Fairly satisfied	-3
Not very satisfied	-1
Not at all satisfied	-0
DK	-2

B. And before you came to live here how satisfied were you with your life as a whole? Would you say you were

Very satisfied	4
Fairly satisfied	3
Not very satisfied	1
Not at all satisfied	0
DK	2

## PATIENT-MORALE

## Dissatisfaction with staff

Source: Interview with patient

Score: Multiply by 100/14

## Items included:

Do you ever feel that

1. Staff don't spend enough time talking to you	Yes = 2 No = 0 DK = 1
2. Staff are always telling you what to do	Yes = 2 No = 0 DK = 1
3. There are not enough staff in the ward	Yes = 2 No = 0 DK = 1
4. There are too many staff in the ward	Yes = 2 No = 0 DK = 1
5. You do not get to know the staff	Yes = 2 No = 0 DK = 1
6. Staff are always changing	Yes = 2 No = 0 DK = 1
7. Staff spend too long with particular patients	Yes = 2 No = 0 DK = 1
Total	= 14

## STAFF-MORALE

## Job satisfaction

Source: Staff self-report questionnaire

Score: Multiply by 100/96

How satisfied or dissatisfied do you feel with each of these features of your present job . . .

1. The physical working conditions
2. The freedom to choose your own method of working
3. Your fellow workers
4. The recognition you get for your work
5. Your immediate superior
6. The amount of responsibility you are given
7. Your rate of pay
8. The opportunity to use your ability
9. Relations between bosses and workers
10. Your chance of promotion
11. The way the ward is managed
12. The attention paid to suggestions you make
13. Your hours of work
14. The amount of variety
15. Your job security
16. Now taking everything into consideration, how do you feel about your job as a whole

Scoring	Extremely dissatisfied	= 0
	Very dissatisfied	= 1
	Moderately dissatisfied	= 2
	Not sure	= 3
	Moderately satisfied	= 4
	Very satisfied	= 5
	Extremely satisfied	= 6
	Total	= 96

## STAFF-MORALE

## Psychological well-being - Bradburn's Affect Balance Scale

Source: Staff self-report questionnaire

Score: Multiply by 5

During the past few weeks have you felt

- |   |                             |
|---|-----------------------------|
| 1. Particularly excited or interested in something                  | Yes = 2<br>No = 0<br>DK = 1 |
| 2. So restless that you couldn't sit long in a chair                | Yes = 0<br>No = 2<br>DK = 1 |
| 3. Proud because someone complimented you on something you had done | Yes = 2<br>No = 0<br>DK = 1 |
| 4. Very lonely or remote from other people                          | Yes = 0<br>No = 2<br>DK = 1 |
| 5. Pleased about having accomplished something                      | Yes = 2<br>No = 0<br>DK = 1 |
| 6. Bored  | Yes = 0<br>No = 2<br>DK = 1 |
| 7. On top of the world  | Yes = 2<br>No = 0<br>DK = 1 |
| 8. Depressed or unhappy   | Yes = 0<br>No = 2<br>DK = 1 |
| 9. That things were going your way                                  | Yes = 2<br>No = 0<br>DK = 1 |
| 10. Upset because someone criticised you                            | Yes = 0<br>No = 2<br>DK = 1 |

Total = 20

## STAFF-MORALE

## Staff worries

Source: Staff self-report questionnaire

Score: Multiply by 100/14

During the past few weeks have you been worried about

1. Not having enough money for day-to-day living	Yes = 2 No = 0 DK = 1
2. Relations with people at work	Yes = 2 No = 0 DK = 1
3. Your health	Yes = 2 No = 0 DK = 1
4. Your family	Yes = 2 No = 0 DK = 1
5. How things are going at work	Yes = 2 No = 0 DK = 1
6. Getting old	Yes = 2 No = 0 DK = 1
7. Worried about other activities	Yes = 2 No = 0 DK = 1
Total	= 14

## Worries about work

Source: Derived from above

Score: Multiply items 2 and 5 by 25

**WORRY ABOUT WORK**

This variable is derived from a subset of the staff worry item. Factor analysis of the responses to the items revealed that two factors exist. The variable 'worry about work' includes items 2 and 5.

# SETTING STANDARDS IN LONG-TERM HOSPITAL CARE

## APPENDIX 1(f)

### PATIENT-ORIENTED POLICIES

Do you think it is appropriate that . . .

There are both smoking and smoke-free rooms	Yes / No / Don't know
There are some separate and some mixed WCs	Yes / No / Don't know
Staff use patients' WCs	Yes / No / Don't know
There is a notice board	Yes / No / Don't know
Ward night lights are kept on at night	Yes / No / Don't know
Patients can change the layout of their bed area	Yes / No / Don't know
Patients can bring their own furniture	Yes / No / Don't know
There are facilities in patients' bed areas for locking away possessions	Yes / No / Don't know
Patients can choose the decor of their bed area	Yes / No / Don't know
The ward has patients' committee	Yes / No / Don't know
Patients are taught new skills	Yes / No / Don't know
Patients can plan their own entertainments and events	Yes / No / Don't know
Patients can design their own menus, over and above choosing from a list	Yes / No / Don't know
Patients can get up when they wish	Yes / No / Don't know
Patients can go to bed when they wish	Yes / No / Don't know

PRIVACY

Do you think it is appropriate that . . .

Patients have privacy whenever they want	Yes / No / Don't know
Patients generally have privacy for entertaining their visitors	Yes / No / Don't know
There is somewhere patients can make phone calls in private (apart from main office)	Yes / No / Don't know
Patients always have the same person to assist them at bathtime	Yes / No / Don't know
Patients can lock up their own rooms	Yes / No / Don't know



CHOICE

Do you think it is appropriate that . . .

Patients have their own cabinets in which they can lock up their personal possessions	Yes / No / Don't know
Patients can choose when they have their full breakfast every day	Yes / No / Don't know
Patients use their bedrooms or bed areas whenever they want	Yes / No / Don't know
There is somewhere patients can make a cup of tea or coffee	Yes / No / Don't know
There is a telephone available for patients' use	Yes / No / Don't know
If assisted, patients can come and go outside the ward whenever they wish	Yes / No / Don't know
Visitors can come at any time	Yes / No / Don't know

ENGAGEMENT

Do you think it is appropriate that . . .

Patients get individual attention

Yes / No / Don't know

A lot of patients just seem to be passing time here

Yes / No / Don't know

Patients are encouraged to maintain their self-care skills

Yes / No / Don't know

Staff encourage patients to help themselves

Yes / No / Don't know

Staff are encouraged a lot to sit and talk with patients are part of their job

Yes / No / Don't know

SPACE AVAILABILITY

Do you think there is adequate . . .

Sitting/dining space

Yes / No / Don't know

Space in the bed areas

Yes / No / Don't know

INVOLVEMENT

Do you think it is appropriate that . . .

Patients have a say in the general organisation  
of this ward

Yes / No / Don't know

ARCHITECTURAL CHOICE

Do you think it is appropriate that . . .

Windows can be opened by the patients in all lounges	Yes / No / Don't know
There is a lounge with no TV	Yes / No / Don't know
Windows can be opened by patients in all dining rooms	Yes / No / Don't know
There is a mixture of large and small tables in the dining area	Yes / No / Don't know
There is a separate shower room in the ward	Yes / No / Don't know
There is/are shower(s) in the bathroom(s)	Yes / No / Don't know
There are separate WCs for men and women	Yes / No / Don't know
There is a patients' shop	Yes / No / Don't know
There is a patients' tea making room	Yes / No / Don't know
There is a chiropody/hairdressing room	Yes / No / Don't know
More than 50 per cent of patients have single bedrooms	Yes / No / Don't know
Patients can control the heating in thier bed areas	Yes / No / Don't know
Patients can open the windows in their bed areas	Yes / No / Don't know
Bed areas contain washhand basins in all areas	Yes / No / Don't know
There are locks on bathrooms/WCs	Yes / No / Don't know

SOCIO-RECREATIONAL AIDS

Do you think it is appropriate that . . .

There is a view of street/garden or street/  
sea (i.e. interesting location) from lounges

Yes / No / Don't know

There is more than one television

Yes / No / Don't know

There is a recreation room for hobbies/  
handicrafts plus bar

Yes / No / Don't know

There is a quiet room

Yes / No / Don't know

There is a visitors' room

Yes / No / Don't know

There is a garden for patients to sit in

Yes / No / Don't know

It is easy for mobile patients to get into  
the garden unaided

Yes / No / Don't know

PHYSICAL AMENITIES

Do you think it is appropriate that . . .

Bedside lights are provided for and can be used by all patients

Yes / No / Don't know

Bed areas have socket outlets which patients can use in all bed areas

Yes / No / Don't know

Patient's room could be used as a bedsitting room

Yes / No / Don't know

DEVELOPMENT OF INSTRUMENT SCHEDULE  
FOR EVALUATION OF INSTITUTIONAL CARE

The aim of this pilot study was to develop a methodology for quality of life evaluation in private nursing home and long-term hospital care.

Populations and Methods

The original methodology was devised following extensive work by Peace et al (1979) for quality of life evaluation in residential care and subsequently used in a national study of residential homes (Willcocks et al, 1987). It includes structured questionnaires for resident morale, regime (policy), environment and staff morale.

Subjects were chosen for ease of access: in 3 private nursing homes in Liverpool, and 3 long-term care wards in Dundee. Interviews were conducted by a medical student (JD) in Liverpool and a senior registrar in geriatric medicine (IP) in Dundee. As results were not intended for comparison, different interviewers and different geographical locations were not considered to reduce the validity of the study.

Patients in each setting were screened for cognitive impairment using a simple mental status questionnaire (MSQ) (Wilson & Brass, 1973). Only those with MSQ  $\geq 7/10$  were further interviewed with the questionnaires for patient morale. Ten hospital and 26 nursing home patients were further interviewed.

All staff present during the visit to each facility were interviewed with the questionnaire for staff morale, with the exception of 7 hospital nurses who declined to be interviewed. Twenty-eight hospital and 27 nursing home staff were interviewed.

The nurses in charge of each ward (3) or home (3) were interviewed with questionnaires for regime and environment. Subjects were asked to indicate whether they understood each question and whether it was of relevance to their setting of care. Questionnaires were modified following responses by subjects.

The questionnaires which included statements which could not be verified by inspection were tested for inter-observer reliability following statistical advice.

The 3 most senior nursing staff present on each of 10 hospital wards were interviewed with these questionnaires. Variation of responses between each nurse on the same ward was compared with variation of responses between wards, using Kappa weighted statistics. A good spread of data between wards was required to produce meaningful statistics. Given a good spread of data, a Kappa weighted statistic  $\geq 0.5$  was the standard set for good inter-observer reliability with higher numbers suggesting better reliability.



## Results

All questions in patient and staff morale questionnaires were understood by subjects and thought relevant to their setting of care. Minor alterations were required for hospital terminology (e.g., home = ward, bedroom = bed area, care staff = nursing staff, resident = patient). Interviews took between 10 and 15 minutes per subject to complete.

Similar alterations were required for environment questionnaires. In addition, alterations were made to take account of single sex wards and for absence of public areas (entrance lobbies, dining rooms, more than one lounge). Questions were understood and thought relevant by subjects. Each interview took about 20 minutes to administer.

Regime questionnaires (the originals are shown in Tables 1-6) required several alterations because subjects found many questions ambiguous or had difficulty with double negatives.

Several alterations were made to improve clarity.

Kappa-weighted statistics for inter-observer reliability were as follows:

Choice: 0.75; Resident-oriented policies: 0.67; Engagement: 0.61; Privacy: 0.60; and Staff-oriented policies: 0.47.

There was poor spread of data for involvement (all scores were zero) preventing statistical analysis.

Each interview with developed questionnaires for regime took about 20 minutes.

For ease of interpretation of results, the scores for each factor on each questionnaire were altered to base 100 with higher scores denoting a higher level of the factor, and scales shifted to zero as the lowest possible score (in the original methodology some factors had negative as well as positive scores).

The developed instrument schedule is shown in Appendix 1(e).

## Discussion

The developed methodology allows quantitative measurement of indicators of quality of life of patients in private nursing homes and long-term hospital wards, and staff morale.

Measurement of quality of life, unlike mortality, is not simple, although scales can inform (Kane & Kane, 1981). The criterion validity of a quality of life scale (does it measure what it purports to?) can only be determined by consensus, the content must be appropriate for the circumstance of its use, it must be clearly understood by respondents, and have demonstrable inter-observer reliability (Ebrahim, 1987).

An attempt was made in this study to develop an instrument whose components meet these standards. Previous work (Peace et al, 1979) suggested criterion validity for the scales. This study established that they were appropriate, with minor modifications, for use in the context of long-term care geriatric wards and private nursing homes. Inter-observer reliability was determined for the scales which were most prone to observer variability and seemed to be reliable.

Other standards for the scales were not established. Test-retest repeatability was not determined, but this was not considered necessary as use in longitudinal study was not envisaged.

The power of the scales to detect differences between different populations was not established. However, when the instrument was used in the comparative study (Study 5) this property emerged.

Wider use of the scales could be applied to populations in long-term hospital and private nursing home care, and could provide much needed information about life in institutional care (Impallomeni & Nicholl, 1990).

Table 1 (APPENDIX)

Choice - Range 0-11

Source: Staff Questionnaire; homes postal questionnaire

Derivation: Additive score with 1 valid case per home.

Items included:

Do residents have somewhere to lock up their personal possessions?	Yes = 1
Is there a fairly set time at which residents are wakened in the morning?	No = 1
Is there a fairly set time at which residents are expected to go to bed at night?	No = 1
Can residents have breakfast . . . Choose time every day?	= 2
Choose time some days?	= 1
Are residents encouraged to use their bedrooms . . . Whenever they want?	= 1
Are residents encouraged to bring their own furniture?	Yes = 1
Is there somewhere residents can make a cup of tea or coffee?	Yes = 1
Is there a telephone available for residents' use?	Yes = 1
Can residents come and go outside the home? Whenever they wish+	= 1
Can visitors come only at set times, or At any time?	= 1

Table 2 (APPENDIX)

Privacy - Range 0-5

Source: Staff questionnaire; homes postal questionnaire

Derivation: Additive score with 1 valid case per home.

Items included:

Do residents have privacy whenever they want?	Yes = 1
Do residents generally have privacy for entertaining their visitors?	Yes = 1
Is there somewhere residents can make phone calls in private (apart from main office)?	Yes = 1
Do residents always have the same person to assist them at bathtime?	Same person = 1
Can residents lock their own rooms?	Yes = 1

Table 3 (APPENDIX)

Involvement - Range 0-5

Source: Staff questionnaire

Derivation: Additive score with 1 valid case per home

Items included:

Do residents have a say in the general organisation of this home?	Yes = 1
Do residents set up their own activities?	Yes = 1
Are residents involved in planning menus?	Yes = 1
Is there a handbook available for new or prospective residents telling them how the home is run?	Yes = 1
Is there a residents' committee held . . . At least once a month	= 1

Table 4 (APPENDIX)

Engagement - Range 0-7

Source: Staff questionnaire; homes postal questionnaire

Derivation: Additive score with 1 valid case per home.

Items included:

Do residents get a lot of individual attention?	Yes = 1
Do staff members sometimes do things for residents that they could do themselves?	No = 1
Are residents taught new skills?	Yes = 1
Can residents get along without doing very much for themselves?	No = 1
Do a lot of residents just seem to be passing time here?	No = 1
Do staff encourage residents to help themselves a lot, a little, or not at all?	A lot = 1
Are staff encouraged to sit and talk with residents, as part of their job?	A lot = 1

Table 5 (APPENDIX)

**Resident-oriented policies - Range 0-17**

Source: Inspector checklist, staff questionnaire

Derivation: Additive score with 1 valid case per home.

Items included:

There are both smoking and smoke-free rooms	= 1
There are some separate and some mixed WCs	= 1
Staff use residents's WCs	= 1
There are emergency unlocking arrangements	= 1
There is a notice board	= 1
Night lights are used only when necessary	= 1
Residents can change the layout of their room	= 1
Residents can bring their own furniture	= 1
There are facilities in residents' rooms for locking away possessions	= 1
Residents can choose the decor of their bedroom	= 1
The home has a residents' committee	= 1
Commodes are used only when necessary	= 1
Residents are taught new skills	= 1
Residents can plan their own entertainments and events	= 1
Residents can design their own menus	= 1
Residents can get up when they wish	= 1
Residents can go to bed when they wish	= 1

Table 6 (APPENDIX)

Staff-oriented policies - Range 0-12

Source: Inspector checklist, staff questionnaire

Derivation: Additive score with 1 valid case per home.

Items included:

Separate WC for the staff	= 1
Night lights are always on	= 1
Commodes are used automatically	= 1
Commodes are used automatically	= 1
Residents have no say in the running of the home	= 1
Residents are not taught any new skills	= 1
Residents do not organise their own activities	= 1
Residents do not organise their own entertainment	= 1
The planning of menus does not involve the residents	= 1
A home handbook is not produced	= 1
Residents get up at a set time	= 1
Residents go to bed at a set time	= 1
There are day attenders	= 1



TABLES

Table 1. Results of Assessments of Suspected Symptomatic Demented Elderly Persons

	Numbers	
Assessed	25	
Symptomatic Dementia	21	
(severe, MSQ 0-3)		7
(moderate, MSQ 4-7)		12
(mild, MSQ 8-10)		2
Not demented	4	
(mental handicap, MSQ = 9)		1
(depression, MSQ = 10)		1
(nocturnal confusion, MSQ = 10)		1
(normal, MSQ = 13)		1

Table 2. Results of Screening of Elderly not Thought to be Demented

Survey Group	Number 60	Percentage	95% Confidence Limits
Refused assessment	9		
Assessed	51		
- no cognitive impairment	33	64.7	52.3 - 77.1*
- mild cognitive impairment and no symptoms	17	33.3	21.0 - 45.5*
- symptomatic dementia	1	1.9	0.2 - 10.9**

\*Formula for the standard error

\*\*Poisson approximation

Table 3. Prevalence of Symptomatic Demented Elderly Persons and of Asymptomatic Elderly with Mild Cognitive Impairment

	Number	Percentage	95% Confidence Limits
Symptomatic Dementia (suspected, subsequently confirmed)	21/534	3.9	
Symptomatic Dementia (found on survey)	1/60	1.7	0.2 - 10.9
Total Symptomatic Dementia		5.8	4.1 - 14.8
Mild Cognitive Impairment, no symptoms	17/51	33.3	21 - 45.5

Table 4. Knowledge about Dementia Before and After Intervention

	Number of carers (of 17) who know each fact	
	Before Intervention	After Intervention
1. Social Services are available	12	14
2. Memory loss may occur	10	14
3. Financial help is available	9	12
4. Nursing services are available	9	14
5. No cure exists at present	9	15
6. Dementia usually progresses	8	15
7. Increased safety at home is needed	8	14
8. Hospital services are available	7	13
9. Relatives can do a lot to help	7	12
10. Wandering may occur	7	14
11. Incontinence may occur	7	14
12. Personality may become less inhibited	5	13
13. Aggressiveness may occur	5	13
14. Apathy may occur	5	12
15. Two main forms of dementia exist	0	2

Table 5. Resource use before and after intervention

Resource	<u>No. of carers (of 17) using each resource</u>	
	Before	After
1. Day hospital	0	0
2. Respite admission	4	6
3. Long term institutional care	0	1
4. Community nursing services	7	9
5. Home help	8	8
6. Meals on wheels	4	2
7. Day centre	2	2
8. Social worker	7	7
9. Alarm system	5	2
10. Laundry service	0	0
11. Incontinence service	2	1
12. Attendance allowance	7	8
13. Additional supplementary benefit	5	4
14. Invalid care allowance	0	0
15. Luncheon club	2	2
16. Relative support group	1	1
17. 'Crossroads' care attendant scheme	3	3
Total	57	56

Table 6. Unmet Resource Needs Before and After Intervention

	Number of carers (of 17) who would like to receive resource*	
	Before Intervention	After Intervention
1. Day centre	7	3
2. Long term institutional care	5	3
3. Respite admission	5	4
4. Attendance allowance	4	0
5. Community nursing services	3	0
6. Luncheon club	3	1
7. Relative support group	3	1
8. 'Crossroads' care attendant scheme	2	1
9. Day hospital	2	0
10. Additional supplementary benefit	1	0
11. Home help	1	0
12. Incontinence service	1	0
13. Invalid care allowance	1	0
14. Laundry service	1	1
15. Alarm system	0	0
16. Meals on wheels	0	2
17. Social worker	0	1
Total	39	17

\*Carers could indicate more than one resource

Table 7. Stress scores before and after intervention

Carer	Stress	
	Before	After
1	5*	3
2	2	4
3	3	1
4	14*	4
5	11*	10*
6	0	0
7	7*	5*
8	15*	13*
9	20*	8*
10	25*	18*
11	10*	1
12	5*	3

\*Denotes "caseness".



Table 8. Service Perceptions (Day Hospital)

Source of Support	(a) In receipt (within last month)*		(b) Knew of		(c) Not known/not received		(d) Needed/not received		(e) Benefit	
	No	%	No	%	No	%	No	%	No	%
Day Hospital	47	100	47	100	0/0	-	0/0	0	0/0	98
Physiotherapy	33	70.2	44	93.6	3/14	21.4	2/14	14.3	2/14	80.6
Occupational therapy	30	63.8	43	91.5	4/17	23.5	1/17	5.9	1/17	81.2
Home help	19	40.4	45	95.8	2/28	7.1	2/28	7.1	2/28	80
Minister/Priest	18	38.3	43	91.5	4/29	13.8	0/29	0	0/29	63.6
Sheltered house	13	27.7	36	76.6	11/34	32.3	4/34	11.8	4/34	78
General practitioner	13	27.7	44	93.6	3/34	8.8	0/34	0	0/34	63.6
District nurse	13	27.7	39	83.0	8/34	23.5	1/34	2.9	1/34	70.8
Meals on wheels	9	19.1	40	85.0	7/38	18.4	1/38	2.6	1/38	68.6
Social worker	5	10.6	32	68.1	15/42	35.7	1/42	2.4	1/42	56
RHE (long-term)	4	8.5	26	55.3	21/43	48.8	1/43	2.3	1/43	92
Laundry	4	8.5	9	19.1	38/43	88.4	3/43	7.0	3/43	70
Other voluntary	3	6.4	3	6.4	44/44	100	0/44	0	0/44	60
Private help	2	4.3	4	8.5	43/45	95.6	1/45	2.2	1/45	80
Day centre	2	4.3	22	46.8	25/45	55.6	9/45	19.8	9/45	86.6
Social club	2	4.3	26	55.3	21/45	46.7	6/45	13.3	6/45	80
Geriatric hospital respite (within one year)	2	4.3	2	4.3	45/45	100	0/45	0	0/45	98
Private nurse	2	4.3	4	8.5	43/45	95.6	0/45	0	0/45	50
Night sitter	1	2.1	4	8.5	43/46	93.5	0/46	0	0/46	80
Lunch club	1	2.1	17	36.2	30/46	65.2	1/46	2.2	1/46	100
Health visitor	1	2.1	9	19.1	38/46	82.6	1/46	2.2	1/46	60
Relative support group	0	0	1	2.1	46/47	97.8	0/47	0	0/47	-
Crossroads	0	0	16	34.0	31/47	66.0	3/47	6.4	3/47	-
Private nursing home	0	0	22	46.8	25/47	53.2	1/47	2.1	1/47	-
Geriatric hospital (long-term)	0	0	4	8.5	43/47	91.5	0/47	0	0/47	-

\*except hospital respite.

Table 9. Service perceptions (Assessment Ward)

Sources	Sources Received		Needed/Not received	
	No.	%	No.	%
Home help	28	59.6	4/19	21.1
General practitioner	28	59.6	8/19	42.1
District nurse	24	51.1	10/23	43.4
Minister/Priest	15	31.9	3/32	9.4
Sheltered housing	11	23.4	9/36	25.0
Meals on wheels	7	14.9	12/40	30.0
Day centre	6	12.8	6/41	14.6
Occupational therapist	5	10.6	2/42	4.8
Health visitor	5	10.6	8/42	19.0
Social worker	4	8.5	3/43	7.0
Physiotherapist	3	6.4	2/44	4.5
Crossroads	3	6.4	3/44	6.8
Day hospital	2	4.3	3/45	6.7
Hospital respite	2*	4.3	3/45	6.7
Private help	2	4.3	1/45	2.2
Social club	1	2.1	4/46	8.7
Lunch club	1	2.1	4/46	8.7
Psychiatrist	1	2.1	0/46	0
Nightsitter	0	0	4/47	8.5
Residential home	0	0	4/47	8.5
Private nursing home	0	0	1/47	2.1
Laundry service	0	0	1/47	2.1
"Other voluntary"	0	0	1/47	2.1
<u>Sources of Support added by relatives</u>				
Church visitors	1	2.1	0/46	0
Bath aid	1	2.1	0/46	0
Chiropody	0	0	1/47	2.1
Unspecified	0	0	1/47	2.1

\*received within last 1 year.

Table 10. Accuracy of carers' expectations of institutionalisation of patients

Carers' predictions	<u>Actual Placement</u>	
	Not institutionalised	Institutionalised
Not institutionalised	22	0
Institutionalised	5	8

2 x 2, Chi-squared test:  $p < 0.001$ .

Table 11. Correlations Between Variables and Institutionalisation

	r*	p
Patients' age	-.0051	.9785
Patients' MSQ	-.2893	.1258
Number of services received	.0155	.9347
Number of unmet service needs	.2197	.2449
Satisfaction with family support	-.2913	.1233
Satisfaction with professional support	-.0795	.6780
Carers' age	-.0102	.9570
Carers' perceived health score	-0.0926	.6241

\*Spearman rank correlations

Table 12. Change in life satisfaction according to relationship

Satisfaction now - then	Relationship:	Spouses	Children	Other relatives
Improved		4	18	0
No change		1	17	16
Deteriorated		3	6	3

Chi-square test 3 x 3,  $p < 0.01$

Chi-square test 3 x 2 (spouses and children vs other relatives),  $p < 0.001$ .

Table 13. Change in life satisfaction according to prior contact

Satisfaction now - then	Support:	Lived with	Daily contact	Weekly or less than weekly contact
Improved		17		5
No change		15		19
Deteriorated		6		6

Chi-square test 3 x 2,  $p < 0.05$ .

Table 14. Mental Status

MSQ	Nursing Home	Geriatric	Psychogeriatric
<7	43	144	183
<u>≥7</u>	10	35	3
<u>Social disruption</u>			
<10	28	67	157
10	25	112	29

Table 15. Disability

Activity	Nursing Home	Geriatric	Psychogeriatric
<u>Bathing:</u>			
Dependent	38	152	185
Independent	15	27	1
<u>Feeding:</u>			
Dependent	4	40	53
Independent	49	139	133
<u>Dressing:</u>			
Dependent	37	133	168
Independent	16	46	18
<u>Toileting:</u>			
Dependent	48	170	158
Independent	5	9	28
<u>Transferring:</u>			
Dependent	43	152	96
Independent	10	27	90
<u>Continence:</u>			
Dependent	32	132	165
Independent	21	47	21

Table 16. Patient Morale

Factor	Nursing Home (10)*	Geriatric (35)*	p
	mean (range)	mean (range)	
Worries	15 (0-63)	17 (0-75)	NS
Change in life satisfaction	43 (0-78)	38 (0-50)	NS
Dissatisfaction with staff	30 (0-57)	42 (0-57)	p<0.05

\*Number of subjects.



Table 17. Environment and Regime

Factor	Nursing Homes (3) mean (range)*	Geriatric Wards (12) mean (range)	Psychogeriatric Wards (8) mean (range)
Space	43 (33-66)	8 (0-33)	0 (0)
Architectural choice	37 (25-45)	19 (5-30)	47.5 (22-75)
Staff facilities	43 (29-58)	58 (43-86)	79 (57-100)
Orientalational aids	14 (0-20)	18 (0-40)	37.5 (0-60)
Prosthetic aids	43 (29-58)	53 (43-71)	46 (29-64)
Socio-recreational aids	50 (50)	41 (12-63)	62 (27-75)
Safety	71 (64-79)	70 (57-93)	57 (38-85)
Amenities	63 (58-68)	55 (47-63)	53 (21-74)
Privacy	34 (20-60)	35 (0-60)	32 (20-40)
Engagement	47 (29-58)	61 (43-100)	66 (29-100)
Choice	52 (36-64)	43 (9-64)	37 (9-71)
Involvement	6 (0-20)	5.3 (0-40)	2.5 (0-20)
Patient-orientated	34 (18-47)	26 (0-41)	26 (12-37)
Staff-orientated	53 (17-75)	66 (50-83)	67 (33-93)

\*Maximum score = 100.

Table 18. Staff Morale

Factor	Nursing Homes Staff (23)	Geriatric Staff (36)	Psychogeriatric Wards Staff (29)
	mean (range)	mean (range)	mean (range)
Worries	15 (0-71)	22 (0-71)	26 (0-86)
Psychological well-being	67 (50-100)	53 (15-90)	75 (30-100)
Job satisfaction	68 (19-85)	59 (19-75)	56 (27-80)

Table 19. Costs of Care (per patient per week)

	Nursing Homes	Geriatric Wards
Long-term geriatric ward costs (Dundee)*		£ 330
- less contribution from State Pension		- 32.90
- less pharmacy costs		- 10.70
- less medical staff costs		- 9.00
Supplementary Benefit to Nursing Home patients	£ 185	
- less contribution from pension		- 31.60
State Pension	£ 41.15	£ 41.15
<b>TOTAL</b>	<b>£ 194.55</b>	<b>£ 318.55</b>

Difference (Hospital - Nursing Home)    £124.00 per patient per week  
 =    £6,448.00 per patient per year

\*Includes medical, nursing and administrative staffing costs; pharmacy; catering; cleaning, laundry and maintenance costs; power and heating.

Table 20. Patient and Staff Perceptions (Long-term Hospital Care)

Statements	Ward Practice (12)	Staff (n=22)	Patients (n=28)	Difference staff vs. patients
	%Yes	%Yes	%Yes	p
1. There is a telephone available for patients' use	42%	95%	100%	NS
2. Patients are encouraged to maintain their self-care skills	33%	100%	100%	NS
3. Staff encourage patients to help themselves	92%	100%	100%	NS
4. There is adequate space in sitting/dining areas	25%	55%	96%	<0.05
5. There are separate WCs for men and women	8%	86%	96%	NS
6. There is a garden for patients to sit in	92%	100%	96%	NS
7. It is easy for mobile patients to get into the garden unaided	50%	91%	96%	NS
8. Patients use their bed area whenever they want	92%	100%	93%	NS
9. There is view of street/garden or street/sea from lounges	92%	100%	89%	NS
10. Patients have privacy when they wish	83%	100%	86%	NS
11. There is somewhere patients can make phone calls in private	17%	91%	86%	NS

Table 20 (continued)

12. If assisted patients can come and go outside ward when they wish	58%	95%	86%	NS
13. Patients are taught new skills	42%	95%	82%	NS
14. Patients go to bed when they wish	75%	100%	79%	NS
15. There is adequate space in bed areas	0%	18%	79%	<0.01
16. Bedside lights are provided for and can be used by all patients	25%	95%	79%	NS
17. Patients have privacy for entertaining visitors	75%	100%	71%	<0.05
18. Staff are encouraged to sit and talk with patients as part of their job	92%	95%	71%	NS
19. There is a patients' shop	58%	91%	71%	NS
20. There is a notice board in ward	58%	100%	68%	<0.05
21. Bed areas have socket outlets which patients can use in all bed areas	83%	73%	68%	NS
22. Staff use patients' toilets	0%	0%	64%	<0.01
23. Visitors can come and go at any time	100%	86%	64%	NS
24. There is a quiet room	0%	91%	64%	NS
25. Patients' rooms can be used as bed-sitting rooms	0%	86%	64%	NS

Table 20 (continued)

26. There are shower(s) in the bathroom(s)	25%	77%	61%	NS
27. There are both smoking and smoke-free rooms	8%	100%	57%	<0.05
28. There are facilities in patients' bed area to lock away possessions	8%	50%	57%	NS
29. The ward has patients' committee	0%	55%	57%	NS
30. There is a chiropody/ hairdressing room	8%	86%	57%	NS
31. There is a lounge with no TV	0%	91%	50%	<0.05
32. There is a visitors room	8%	95%	50%	<0.05
33. Ward lights are kept on at night	92%	82%	46%	<0.05
34. There is somewhere patients can make a cup of tea or coffee	0%	55%	46%	NS
35. There is a patients' tea-making room	0%	45%	46%	NS
36. There is a mixture of large and small tables in dining area	25%	86%	43%	<0.05
37. There is a separate shower room in the ward	58%	82%	43%	<0.05
38. Patients can control heating in their bed areas	0%	42%	43%	NS
39. There is more than one television	42%	68%	43%	NS
40. Lots of patients seem to be just passing time here	75%	45%	36%	NS
41. Patients can lock up their own rooms	0%	0%	32%	<0.05

Table 20 (continued)

42. Patients can change the lay-out of bed areas	17%	50%	29%	NS
43. Patients plan their own entertainments and events	58%	95%	29%	<0.01
44. Patients get up when they wish	67%	91%	29%	<0.01
45. There are locks on bathrooms/WCs doors	50%	32%	29%	NS
46. Bed areas contain washhand basins in all areas	25%	86%	29%	<0.01
47. There is a recreation room for hobbies plus a bar	0%	82%	29%	<0.05
48. Patients choose decor of bed areas	8%	59%	25%	<0.05
49. Patients get individual attention	100%	91%	25%	<0.01
50. Patients can bring their own furniture	0%	50%	21%	NS
51. Patients design their own menus	8%	59%	18%	<0.05
52. There are some separate and some mixed toilets	50%	68%	14%	<0.01
53. More than 50% patients have single rooms	0%	50%	14%	<0.05
54. Patients can open the windows in their bed areas	-	33%	14%	NS
55. Patients always have same person to assist them at bathtime	0%	5%	14%	NS
56. Patients choose when they have breakfast every day	8%	27%	11%	NS

Table 20 (continued)

57. Patients have a say in the general organisation of the ward	17%	55%	11%	<0.05
58. Windows can be opened by patients in all lounges	0%	18%	11%	NS
59. Windows can be opened by patients in all dining rooms	0%	18%	11%	NS



Table 21. Significantly more staff than patients in favour

Patients have privacy for entertaining visitors.

There is a notice board in ward.

There are both smoking and smoke-free rooms.

There is a lounge with no TV.

There is a visitors room.

Ward lights are kept on at night.

There is a mixture of large and small tables in dining area.

There is a separate shower room in the ward.

Patients plan their own entertainments and events.

Patients get up when they wish.

Bed areas contain washhand basins in all areas.

There is a recreation room for hobbies plus a bar.

Patients choose decor of bed areas.

Patients get individual attention.

Patients design their own menus.

There are some separate and some mixed toilets.

More than 50% patients have single rooms.

Patients have a say in the general organisation of the ward.

Table 22. Minority ward practice and majority patient preference

Statement	Patients in favour (%)	Wards practice (%)
There is a telephone available for patients' use	100%	42%
Patients are encouraged to maintain their self-care skills	100%	33%
There are separate WCs for men and women	96%	8%
There is somewhere patients can make a phone call in private	86%	17%
Patients are taught new skills	82%	42%
Bedside lights are provided for and can be used by all patients	79%	25%
Staff use patients' toilets	64%	0%
There is a quiet room	64%	0%
There are shower(s) in the bathroom(s)	61%	25%
There are both smoking and smoke-free rooms	57%	8%
The ward has patients' committee	57%	0%
There are facilities in patients' bed area to lock away possessions	57%	8%
There is a chiropody/ hairdressing room	57%	8%

Table 23. Standards Set for Ward Life

Choice

1. There is a telephone available for patients' use
2. Patients use their bed area whenever they want
3. If assisted patients can come and go outside ward when they wish

Patient-oriented policies

4. There are separate WCs for men and women
5. Patients are taught new skills
6. Patients go to bed when they wish
7. There is a notice board in ward
8. There are both smoking and smoke free rooms
9. There are facilities in patients' bed area to lock away possessions
10. The ward has patients' committee

Privacy

11. Patients have privacy when they wish
12. There is somewhere patients can make phone calls in private
13. Patients have privacy for entertaining visitors

Architectural choice

14. There is a patients' shop
15. There are shower(s) in the bathroom(s)
16. There is a chiropody/hairdressing room
17. There is a lounge with no TV

Physical amenities

18. Bedside lights are provided for and can be used by all patients
19. Bed areas have socket outlets which patients can use in all bed areas

Socio-recreational aids

20. There is a garden for patients to sit in
21. It is easy for mobile patients to get into the garden unaided
22. There is view of street/garden or street/sea from lounges
23. There is a visitors room

Engagement

24. Patients are encouraged to maintain their self-care skills
25. Staff encourage patients to help themselves
26. Staff are encouraged to sit and talk with patients as part of their job