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Survey of Admissions to Residential and Nursing Home Care

Final Report of the 30 Month Follow-Up

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Discussion Paper 1623

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Chapter 1 Introduction

- This report builds on a previous report on the third follow-up of individuals included in the 1995 PSSRU Survey of Admissions to Residential and Nursing Homes. The survey provides a unique perspective on what happens to publicly funded residents after admission, allowing us to relate characteristics on admission to subsequent events. The introductory chapter describes the structure of the report and details the methodology and development of the longitudinal database.

Chapter 2 People from Black and Ethnic Minorities

- Ethnic minorities do not appear to have a low level of admission to local authority funded care homes, and may even have a higher than average rate, if we allow for age differences. However the health of those admitted is in general somewhat poorer, and possibly they live less long, which seems to indicate that they have left it late to be admitted.

- This would imply that the low health expectancy of people in ethnic minorities means that care services are needed earlier, and that to achieve equity with whites rather higher admissions rates might be expected than at present. Although our evidence is limited, as far as it goes it does appear to support the allegation that there are problems of access for people in black and ethnic minority groups, assuming, of course, that no equally good substitute services are available.

- This evidence would also imply that the expected rise of numbers of elderly people in ethnic minorities will, if the health differentials remain, give rise to a disproportionate rise in the need for care, and hence to increased demand should the access problems be resolved.

Chapter 3 Moves within Residential and Nursing Home Care

- Approximately 8 per cent of the individuals included in the admissions survey were recorded as having moved to a different home and 6.6 per cent were recorded as having moved to a different type of bed. Including individuals who were admitted to a nursing bed from a residential home suggests that approximately 17 per cent of individuals admitted to a residential bed subsequently move to a different type of bed.

- Individuals admitted to a residential bed were more likely than those admitted to a nursing bed to have moved to a different home or to a different type of bed. Individuals admitted to dual registered homes were less likely to have moved to another home but more likely to have moved to a different type of bed than individuals in the survey as a whole, and the majority moved from a residential to a nursing bed.

- Individuals who moved to a different home or type of bed were more likely to have survived to the 30 month follow-up than those who remained in the same home or type of bed, an unexpected finding for those who moved from a residential bed to a nursing bed.

- Individuals who moved from a nursing bed to a residential bed had lower levels of dependency on admission than those who remained in the same type of bed or who left nursing home care. People who moved from a residential bed to a nursing bed had similar levels of dependency on admission to those who remained in the same type of bed. Individuals who left residential care had lower levels of dependency than those who remained in residential or nursing home care.

- Individuals who moved to a different type of bed were more likely to have been predicted to have been admitted to that type of bed than those who remained in the original type of bed. However, the association between the predicted location and the destination was much weaker for those admitted to a residential bed than for those admitted to a nursing bed.

Chapter 4 People who leave Residential and Nursing Home Care

- Few people appear to leave a care home environment once admitted. The great majority of those that do, leave fairly soon after admission. Thereafter there would seem to be an effort made to retain the resident in the home wherever possible. We cannot conclude on the basis of subsequent moves that there is much evidence of misplacement at admission.

- Though failure to settle was given as the commonest reason for discharge back to private households, it is evident that the majority of such people had been admitted at low levels of dependence and the health of others had improved. Though informal care is often a factor enabling discharge, a significant number returned to live alone (possibly in sheltered housing). This group had better survival prospects than those remaining in a care home.

- Rehabilitation was considered for 6 per cent of people at the time of admission, but rarely resulted in them returning home. Only a few of the people who were actually discharged

to a private household had been admitted with rehabilitation in mind. Nevertheless, those local authorities that were most minded to consider rehabilitation, did indeed discharge the most cases, even if they were not the ones originally planned.

Chapter 5 Length of Stay and Mortality

- The median survival for the whole sample is 19.0 months ($\pm$ 0.8 months). For those originally admitted to nursing homes it is 11.0 months ($\pm$ 0.9 months), and for residential care is 25.7 months ($\pm$ 0.9 months).

- The factors at admission that significantly raise subsequent mortality are, in order of their statistical significance: having a malignancy (cancer), having a low Barthel score (high disability), old age, being a man, being admitted to a nursing home, being admitted from a hospital, having a respiratory illness.

- There are no significant differences between local authorities in survival outcomes, after taking into account factors such as dependency on admission.

- As a few residents will live for a long while, the average length of survival is much greater than the median. Given the evidence to 30 months, our best estimate is 28½ months and almost certainly in the range 25½ - 32 months. This is much less than recent speculation, but the model very tentatively forecasts about 5 per cent of people will survive 8 years or longer after admission.

Chapter 6 Health Outcomes of people admitted to Care Homes

- With regard to both dependency and cognitive function, the evidence suggests that survivors at 6 months may on average, be a little better off than at the time of admission, but thereafter there will be a slow but steady decline. The improvement by 6 months is most marked in those activities of daily living that might relate to being in a better controlled environment, rather than any real indication that people have recovered in a way that might make them more fit to return to private households.

- People who are comparatively independent at time of admission improve most. What is particularly noticeable is that it is people with specific health diagnoses on admission that are the most likely to improve. However, surprisingly, these are not people discharged from hospital. More of the people admitted from private households improve.

- This suggests it is not premature discharge from hospital that provides the greatest missed opportunities for possible rehabilitation. Rather it is among people admitted from private households with chronic diseases. Possibly these are diseases that may undergo remission, and thus enable the person to be more independent, at least for a while.

- A Markov model is introduced to measure the expectation of life at different states of health, both in terms of dependency and cognitive functioning. The expected time at different states of dependency very much depends on health at the outset. Ultimately however, everyone can expect to live for about 4 months in a state of total dependency (Barthel scores 0-4).

- Though some people seem quite independent and mentally alert at each stage of the survey, only one per cent of all those admitted were in this condition at every wave of the survey. The implication is that there is not a large and obvious group for whom a placement in a care home is clearly inappropriate on health grounds.

Chapter 7 Life-time Costs within a Care Home

- The average gross lifetime cost to social services of a placement is predicted as £27,000 for initial admission to a nursing bed and £36,000 for a residential bed (1995/6 prices). There is tremendous variation in life-time costs and about six per cent of people admitted will cost more than £100,000. These estimates depend on survival beyond 30 months, but are likely to be within 15 per cent of these figures.

- Net lifetime costs are harder to judge because of problems establishing the client contribution. The cost is much higher in local authority residential homes compared with other types of accomodation. Given the central forecast of survival it likely to be £31,000 - £34,000 for a placement in an LA home (excluding capital costs), £17,000-£19,000 in other residential homes, and £16,000-£18,000 in a nursing home.

- Where estimation of lifetime costs must be made prior to a placement decision, a prediction formula is given. However, those factors, which raise weekly costs (by leading to nursing rather than residential care), are precisely those that lower expected survival. The consequence is that while lifetime cost may be predicted from circumstances at the outset, the great variation means such estimates cannot be expected to be very accurate in individual cases.

Chapter 1
Introduction

1.1 Introduction

This report builds on a previous report on the third follow-up of individuals included in the 1995 PSSRU Survey of Admissions to Residential and Nursing Homes (Bebbington et al., 1999). The survey provides a unique perspective on what happens to publicly funded residents after admission, allowing us to relate characteristics on admission to subsequent events.

We start by providing in this chapter a complete description of the tracking process and the locations of residents at each of the three stages of the longitudinal study. Previous reports and papers which have described the characteristics of people admitted have focused on dependency, circumstances of admission and household characteristics overall (see for example Netten et al., 1999). We take the opportunity in chapter 2 to explore an area of key policy concern: what evidence there is about access to publicly funded care in care homes for those from black and ethnic minorities. However, our primary concern is what happens to people and the degree to which we can predict this from characteristics on admission. Chapter 3 explores the degree to which people move once they have been admitted: between homes and, of most financial consequence, between types of bed. Chapter 4 focuses on a group of movers of particular interest: those who leave care homes entirely. Chapter 5 recaps and updates a previous analysis predicting length of stay and mortality among residents, key factors in predicting long term costs. Chapter 6 considers how health states change during the first few years after admission. Finally, chapter 7 brings together information about "care careers" and mortality to predict life-time costs after admission to a care home.

1.2 The Survey

The survey included 2629 individuals who were admitted from 18 local authorities to residential and nursing home care during a three-month period in the autumn of 1995, as long-stay, local authority supported residents aged 65 or over. The follow-ups were conducted six months, 18 months, 30 months and then 42 months after admission.

The information collected in the admissions survey was provided by social services staff in the 18 participating local authorities. In the follow-ups, home managers were asked to complete a questionnaire to record the location of the elderly person and, if they were still resident in the

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home, information on their level of dependency. The information on dependency was designed to correspond to the information recorded in the admissions survey. For those elderly people who were no longer in the home, respondents were asked to record their destination and the date of departure or death. If an elderly person had moved to another residential or nursing home, the new home was contacted and asked to complete the same questionnaire. Separate exercises were conducted in parallel to each of the follow-ups, to follow up those elderly people who left the home to return to a private household or who were discharged to hospital without their bed in the home being kept open. Information about these cases was obtained from the local authority which made the original assessment for admission and, except for the 42 month follow-up, included information on dependency for individuals who were still alive and who had not returned to residential or nursing home care. Those re-admitted to a residential or nursing home were then included in the main series of follow-up studies. The results from the first three follow-ups, including information about those elderly people who returned to a private household or who were discharged to hospital, have been presented in three previous papers (Darton and Brown, 1997; Bebbington et al., 1998, 1999).

1.3 Development of the Database

The full database for the admissions survey included 2629 individuals. However, the survey included two groups of individuals who were included at the request of two of the participating local authorities: 66 individuals in the first local authority were on a waiting list for admission; and three individuals in the second local authority were receiving alternative packages of care to residential or nursing home care. In addition, 15 individuals were aged under 65 years, including one of the waiting list cases, and three were found to be short-term admissions. The three short-term admissions include one individual who was not identified as such in the analyses reported in previous papers.

The information presented in the previous papers on the results of the six month, 18 month and 30 month follow-ups was based on 2544 individuals included in the admissions survey, following the exclusion of 85 of the 86 out-of-scope cases described above. This chapter is based on 2543 cases, excluding the additional short-term admission. In addition, one case was subsequently reported to be a duplicate case. As in the previous papers, the cases have not been weighted for the purposes of the analyses presented in this chapter.

The original survey in autumn 1995 included a check on the location of the elderly people one month after admission. One hundred and seventy two individuals were reported to have died and 64 individuals were reported as having moved to another location within one month of

admission. In addition, separate information was obtained on the death of 28 individuals, of whom four had moved to another location within one month of admission. At the six month follow-up, information was obtained for 1920 of the 2543 individuals included in the analysis of the admissions survey, including two cases reported to have died within one month of admission, although the information on location at the six month follow-up was incomplete for three cases. No information was obtained at the six month follow-up for 42 of the 60 individuals who were reported as having moved to another location within one month of admission, but who were not reported to have died, and the information obtained on the location of these cases one month after admission was used as the location at six months. As a result of these adjustments, information was available for 2157 cases, 85 per cent of the 2543 individuals included in the analysis of the admissions survey. However, separate information was also obtained on deaths within the first six months and, in addition, further information on deaths by six months was obtained at the subsequent follow-ups. This accounted for a further 196 deaths. For 132 of these individuals their location at six months was previously classified as unknown. Thus the information on location at six months presented below is based on 2289 cases. The cases who were not followed up at six months included 44 individuals who refused to be included in the follow-up and eight cases who were untraceable. For 30 of the 743 deaths recorded at the six month follow-up, the date of death occurred more than six months after admission. However, this problem was largely overcome in the questionnaires used for the subsequent follow-ups by improving the instructions on the questionnaires.

The 18 month follow-up included individuals who were alive, traceable and who had not previously refused to take part in the study. One thousand, eight hundred and thirty-one of the 2629 cases in the full database remained after excluding cases who were recorded as having died at the time of the six month follow-up, those who refused and those who were untraceable. Additional information obtained from homes and local authorities between the six month and 18 month follow-ups, together with information from the six month follow-up, identified a further 431 cases who had died, or who had moved to a private household or who had been discharged to hospital. Excluding these cases, and the three individuals included in the admissions survey who were receiving alternative packages of care, resulted in a total of 1397 individuals for whom an 18 month follow-up questionnaire was sent to home managers. Information was obtained for 1161 of the 1397 individuals covered by the 18 month follow-up (83 per cent), of whom 1127 were included among the 2543 cases used in the analyses presented in this report. The cases who were not followed up at 18 months included 32 individuals who refused to be included in the follow-up and eight cases who were untraceable or ineligible, for example those who were self financing. Among the 1127 cases for whom information was obtained at the 18 month follow-up, 120 were recorded as having died, four were recorded as having moved to a private household and 11 were recorded as having been discharged to hospital.

The information obtained at the 18 month follow-up has been combined with information obtained at the six month follow-up, and additional information on deaths, moves to a private household and discharges to hospital, to provide comprehensive information on location at the 18 month follow-up. As for the information presented on the six month follow-up, the information presented on location at 18 months incorporates some separate information on deaths within the first six months and further information obtained at the subsequent, 30 month follow-up. The information on location at the 18 month follow-up includes the deaths of 129 individuals whose location was classified as unknown in the 18 month follow-up. The information on location at 18 months presented below is based on 2263 cases.

The methodology used for the 18 month follow-up was repeated for the 30 month follow-up. Beginning with the 1831 cases identified for the 18 month follow-up, 1269 remained after excluding cases who were recorded as having died prior to or during the 18 month follow-up, those who refused, those who were untraceable or ineligible, the three individuals included in the admissions survey who were receiving alternative packages of care, and a duplicate case. Additional information obtained from homes and local authorities between the 18 month and 30 month follow-ups identified a further 296 cases who had died, or who had moved to a private household or who had been discharged to hospital. Excluding these cases resulted in a total of 973 individuals for whom a 30 month follow-up questionnaire was sent to home managers. Information was obtained for 819 of the 973 individuals covered by the 30 month follow-up (84 per cent), of whom 800 were included among the 2543 cases used in the analyses presented in this chapter. The cases who were not followed up at 30 months included 11 individuals who refused to be included in the follow-up and two cases who were untraceable. Among the 800 cases for whom information was obtained at the 30 month follow-up, 84 were recorded as having died, four were recorded as having moved to a private household and seven were recorded as having been discharged to hospital. As for the previous follow-ups, the information obtained at the 30 month follow-up has been combined with additional information on deaths, moves to a private household and discharges to hospital, to provide comprehensive information on location at the 30 month follow-up. The information on location at 30 months presented below is based on 2300 cases.

1.4 Location of Elderly People at Six Month, 18 Month and 30 Month Follow-Ups

Tables 1.1 and 1.2 present information on the location of the elderly people at the six month, 18 month and 30 month follow-ups, after incorporating the adjustments to each set of follow-up data described in section 1.2. These adjustments include information on deaths of individuals who had moved to a private household or who had entered hospital. Thus, the proportions of

deaths at six months and 18 months are higher than the corresponding figures shown in the reports on the six month and 18 month follow-ups (Darton and Brown, 1997; Bebbington et al., 1998). The information presented in tables 1.1 and 1.2 also incorporates amendments to the location of individuals obtained in the follow-ups of people who left the home to return to a private household or who were discharged to hospital. The type of bed to which the individuals were originally admitted refers to the type of bed recorded in the admissions survey, and does not necessarily correspond to the type of bed to which individuals who were already in residential or nursing home care were first admitted.

As noted above, information on the location of individuals at six months was obtained for 2289 of the 2543 individuals included in the admissions survey (90 per cent). Of these 2289 cases, 62 per cent were still in the same type of bed as on admission, 32 per cent had died, 2 per cent had moved to a different type of bed, 2 per cent had moved to a private household and one per cent had entered hospital. At 18 months, information was obtained on the location of 2263 individuals (89 per cent). Of these 2263 cases, 39 per cent were still in the same type of bed as on admission, 53 per cent had died, 4 per cent had moved to a different type of bed, 2 per cent had moved to a private household and ten individuals had entered hospital. At 30 months, information was obtained on the location of 2300 individuals (90 per cent). Of these 2300 cases, 27 per cent were still in the same type of bed as on admission, 67 per cent had died, 4 per cent had moved to a different type of bed, 2 per cent had moved to a private household and 11 individuals had entered hospital.

Individuals admitted to a nursing bed in autumn 1995 were more likely than those admitted to a residential bed to have died by the six month follow-up, and less likely to be in the same home or to have moved elsewhere, either to hospital or to a private household. Among the individuals for whom follow-up information was obtained, 45 per cent of those originally admitted to a nursing bed had died, compared with 21 per cent of those originally admitted to a residential bed, while 52 per cent of those originally admitted to a nursing bed and 70 per cent of those originally admitted to a residential bed were still in the same type of bed. By the 18 month follow-up, 67 per cent of those originally admitted to a nursing bed had died, compared with 42 per cent of those originally admitted to a residential bed, while 28 per cent of those originally admitted to a nursing bed and 49 per cent of those originally admitted to a residential bed were still in the same type of bed. By the 30 month follow-up, 77 per cent of those originally admitted to a nursing bed had died, compared with 59 per cent of those originally admitted to a residential bed, while 19 per cent of those originally admitted to a nursing bed and 33 per cent of those originally admitted to a residential bed were still in the same type of bed.

Table 1.3 presents information on the destination of the elderly people who left residential or nursing home care within 30 months of admission, by their location at the 30 month follow-up. A total of 86 individuals (3 per cent of all individuals) were recorded as having moved to a private household and a total of 89 individuals (3 per cent) were recorded as having been discharged to hospital during the 30 months following admission. In addition, two individuals who were recorded as having moved to a private household and five who were recorded as having been discharged to hospital were recorded as having died on the same day. These individuals were included with the 1446 deaths in table 1.3. Among those who had moved to a private household, 43 per cent were still in a private household at 30 months, 14 per cent had returned to residential or nursing home care or were in hospital, and 42 per cent had died. Among those who had been discharged to hospital, 11 per cent were still in hospital and 79 per cent had died.

Table 1.1: Location of individuals at 6 month, 18 month and 30 month follow-ups

Location	6 months		18 months		30 months	
	No.	%	No.	%	No.	%
Total number of individuals	2543	100.0	2543	100.0	2543	100.0
Originally admitted to residential bed	893	35.0	656	25.8	469	18.4
Same type of bed	849	33.4	592	23.3	406	16.0
Moved to nursing bed/home	44	1.7	64	2.5	63	2.5
Originally admitted to nursing bed	570	22.4	334	13.1	231	9.1
Same type of bed	559	22.0	299	11.8	208	8.2
Moved to residential bed/home	11	0.4	35	1.4	23	0.9
Elsewhere	83	3.3	66	2.6	48	1.9
In hospital (bed not being kept open)	29	1.1	10	0.4	11	0.4
In private household	54	2.1	56	2.2	37	1.5
Died	743	29.2	1207	47.5	1552	61.0
No information	254	10.0	280	11.0	243	9.6

Table 1.2: Location of individuals at 6 month, 18 month and 30 month follow-ups, by type of bed to which originally admitted

Location	6 months				18 months				30 months			
	Admitted to residential bed		Admitted to nursing bed		Admitted to residential bed		Admitted to nursing bed		Admitted to residential bed		Admitted to nursing bed	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Total number of individuals	1369	100.0	1174	100.0	1369	100.0	1174	100.0	1369	100.0	1174	100.0
In a residential or nursing home	893	65.2	570	48.6	656	47.9	334	28.4	469	34.3	231	19.7
In same type of bed originally admitted to	831	60.7	539	45.9	583	42.6	297	25.3	402	29.4	203	17.3
In another residential bed/home	18	1.3	11	0.9	9	0.7	35	3.0	4	0.3	23	2.0
In another nursing bed/home	44	3.2	20	1.7	64	4.7	2	0.2	63	4.6	5	0.4
Elsewhere	60	4.4	23	2.0	48	3.5	18	1.5	35	2.6	13	1.1
In hospital (bed not being kept open)	20	1.5	9	0.8	9	0.7	1	0.1	8	0.6	3	0.3
In private household	40	2.9	14	1.2	39	2.8	17	1.4	27	2.0	10	0.9
Died	261	19.1	482	41.1	500	36.5	707	60.2	717	52.4	835	71.1
No information	155	11.3	99	8.4	165	12.1	115	9.8	148	10.8	95	8.1

Table 1.3: Destination of individuals who had left residential or nursing home care within 30 months of admission, by location at 30 month follow-up (number of cases)

Destination	Residential bed	Nursing bed	Hospital	Private household	Died	No information	All individuals
Number of individuals	429	271	11	37	1552	243	2543
Destination							
Residential or nursing bed	420	264	-	-	-	-	684
Hospital	1	4	10	0	70	4	89[1]
Private household	8	3	1	37	36	1	86[2]
Died	-	-	-	-	1446	-	1446
No information	-	-	-	-	-	238	238

Notes: 1. Excluding 5 deaths on the date of discharge.
2. Excluding 2 deaths on the date of discharge.

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Chapter 2
People from Black and Ethnic Minorities

2.1 Introduction

Concern has been expressed about the special needs of older people from ethnic minorities for publicly funded residential and nursing home care, as indeed for social services designed for the elderly generally. These concerns have hinged on matters of cultural appropriateness; for example one of the recommendations of the Royal Commission on Long Term Care (1999) was that "it should be a priority for Government to improve cultural awareness in services offered to black and ethnic minority elders", and the suitability of current modes of care has been questioned (Askham et al., 1995; Patel, 1999).

'Appropriateness' broadly concerns the quality of the care being offered, which is beyond the main scope of the present survey. Awareness of this subject is now widespread through social services and has been formally expressed in relevant governmental papers through the 1990's, and Murray & Brown (1998) list examples of local good practice. What is less well known is to what extent existing services are used by people from black and ethnic minorities, and what is the pattern of use. The assumption seems to be that they are underused by these groups, and therefore that *ease of access* should also be of concern. Patel (1999, para 3.2) describes existing levels of provision as 'inadequate', not just because of shortage of supply, as measured by range and choice of services, but because services are culturally inappropriate. In other words, there is a link between access and quality in that people will be reluctant to access an unsuitable service. Special problems of access exist for ethnic minorities in areas where there are particularly small numbers of such people, and consequently for the informal carers who may suffer from the consequence of these inadequacies.

The numbers of elderly people from the ethnic groups of most concern – those from the 'New Commonwealth' who have emigrated to Britain since the 1950's – do remain small. Latest estimates (Schuman, 1999) indicate that by 1996 they comprised less than 2 per cent of all people over 60, and well under 1 per cent of all those over 75, the main age group for these services. Nevertheless numbers may be expected to increase as the younger immigrants age, though arguably the cultural distinctions and obstacles may diminish as they do so.

The admissions survey identified only 29 people from the main black and ethnic minority groups who were admitted as publicly funded residents over 65 of care homes during the end

of 1995 in the local authorities in the study[1]. This includes people described as African or Caribbean in origin, Asian sub-continent (Bangladeshi, Indian, Pakistani) or Chinese. Clearly only limited inference can be drawn from such a small group, and while we can re-iterate the importance of cultural diversity and the quite different problems and experiences of people in these groups, there is little we can do to investigate them statistically in a systematic way. Nevertheless there must be some shared experience among all ethnic minorities who come to live in a predominantly white culture.

2.1.1 Representativeness

The admissions survey was designed to be nationally representative (of England). From the 1991 Census, the proportion of people from ethnic minorities in these 18 authorities is identical to the national average. It is of concern however that in 125 (5 per cent) of cases out of the 2577 cases in this study, ethnic identification was not reported. It should be remembered that reports were by social workers, not by the individuals themselves. One hundred and fifteen of these 'unknowns' came from just 3 of the local authorities in the study. This included: (i) a large southern county, with an average proportion of people from ethnic minorities; (ii) a large northern city, with an above average proportion; (iii) an outlying northern metropolitan area, with a very low proportion. Non-reporting seemed to be the result of team decisions in these areas. For example one team was unwilling to complete this question without first contacting and asking their clients how they would rate themselves. If we assume that the fact of non-response was for reasons unrelated to the actual ethnic status of individuals, then there is no reason to believe that the resulting completed sample will be biased. It is certainly not plausible that all, or even a large proportion of these missing reports concerned people from ethnic minorities.

2.2 Admission Rates from Ethnic Minorities

For this analysis we concentrated on the three ethnic minorities described in §2.1. Individuals in 'European' ethnic minority groups (mostly Irish and Cypriot) are combined with 'white'. Fourteen people described as 'other' or mixed race have been excluded from this analysis. (For full details of the recorded categories and our classification, see Table 2.1.)

At the time of the 1991 Census there were just 1.3 per cent of the population aged 65 from these ethnic groups, after allowing for under-reporting, and even by 1996 the proportion can

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[1] There was one other of unknown age. In keeping with the rest of this report, this person has been dropped from the analysis.

have increased very little. Our survey found 29 out of 2438 or 1.2 per cent (with a standard error of ±0.2 per cent). From this it would seem that the number admitted is not very different from the representation in the population.

But it may be important to take into account the very different age compositions of the white and ethnic minority groups. Because many of those in ethnic minority groups emigrated to Britain comparatively recently, even among the elderly population they tend to be younger than average, and as we noted above, there are very few over 75. This is reflected in the age distribution of those admitted, where many are under 75, a comparatively low risk group generally. If we standardise for the population age differences, then it would appear that the admission rate among ethnic minorities is 1.9 times as great as for whites. The analysis on which this is based is shown in the appendix. There are more admissions than expected particularly among the Afro-Caribbean and Chinese subgroups, though of course numbers are very small.

2.3 Characteristics of people admitted

As well as in their age composition people from ethnic minorities differ from whites in other ways. Table 2.2 summarises results based on a range of factors at the time of admission. There are some striking differences between ethnic minority and white admissions. Those from ethnic minorities are, in general:
- Younger;
- More men;
- More likely to have been living with their family prior to admission;
- Higher incidence of cognitive impairment/dementia and incontinence.
- Are more dependent scored on the Barthel scale.

Despite the higher dependence, physical health problems are less likely to feature among the list of reasons for admission than for whites, while mental health problems, housing and carer difficulties are more likely.

While we are wary of making observations about ethnic subgroups in view of the very low numbers involved, it is worth noting that most of the above observations apply particularly to the African & Afro-Caribbean group. Those from the Indian Sub-Continent are more like whites, though this group record a number of problems with carers.

2.4 Consequences of admission

Table 2.3 shows placement after admission. There is little difference between whites and those from ethnic minorities in placement decisions. Like whites, very few return to private households after admission.

The median survival following admission for people from ethnic minorities is 14 months, compared with 18 months for whites. The difference is not statistically significant, but is consistent with the lower dependency on admission. Again there seem to be differences between ethnic subgroups, with people from the African & Afro-Caribbean group dying more quickly than others and Asian persons more likely to survive longer.

2.5 Conclusion

We therefore conclude that, contrary to what is often stated, ethnic minorities do not have a low level of admission to local authority funded care homes, and may even have a higher than average rate, if we allow for age differences. However the health of those admitted is in general somewhat poorer, and possibly they live less long, which seems to indicate that they have left it late to be admitted. This would imply that the low health expectancy of people in ethnic minorities means that care services are needed earlier, and that to achieve equity with whites rather higher admissions rates might be expected than at present. Although our evidence is limited, as far as it goes it does appear to support the allegation that there are problems of access for people in black and ethnic minority groups, assuming, of course, that no equally good substitute services are available. This evidence would also imply that the expected rise of numbers of elderly people in ethnic minorities will, if the health differentials remain, give rise to a disproportionate rise in the need for care, and hence to increased demand should the access problems be resolved.

Table 2.1:Ethnic classifications within the admissions study simplified into groups

Ethnic Classification Reported	*Simplified Ethnic Classification*
UK White Irish Turkish Cypriot Greek Cypriot White European European UK White British White Other/ Other White	White
Black African Black Caribbean/ Caribbean Black Other Black British Black African Somali Other African	Afro-Caribbean
Indian Bangladeshi Pakistani	Asian
Chinese	Chinese
Mixed Other Not Known Not asked Not Disclosed	Unclassified

Table 2.2: Characteristics on admission of people from ethnic minorities

	White		Black & Ethnic Minorities		Significance Test	
	N	*%*	*N*	*%*	*Chi-Sq*	*p*
Area of Origin					18.6	0.00
Shire Counties	1162	48	8	28		
Metropolitan Districts	996	41	11	38		
London	249	11	10	44		
Gender					4.8	0.03
Male	710	30	14	48		
Female	1696	70	15	52		
Age group					16.0	0.00
65-74	290	12	10	36		
75-84	1019	42	12	43		
85+	1089	46	6	21		
Household composition					5.9	0.02
Lived alone	1259	64	9	39		
Lived with others	718	36	14	61		
Admitted from					2.7	0.26
Hospital	1248	52	17	59		
Community	803	34	10	34		
Care home/other	345	14	1	7		
Barthel score					3.4	0.07
Low dependence (13-20)	821	34	6	21		
Moderate dependence (9-12)	570	24	5	17		
Severe dependence (5-8)	554	23	11	38		
Total dependence (0-4)	456	19	7	24		
Confusion					2.6	0.11
Cognitively intact	460	20	2	7		
Mild confusion	1031	45	13	48		
Severe confusion	787	35	12	44		
Incontinent					12.3	0.00
No	1712	71	12	41		
Yes	695	29	17	59		
Diagnosed at admission with						
Dementia	922	38	17	59	5.0	0.03
Cardio-vascular disease	466	19	6	21	0.0	0.86
Respiratory disease	357	15	0	0	5.0	0.03
Malignancy	199	8	2	7	0.7	0.79
Stroke	501	21	9	31	1.8	0.18
Arthritis	771	32	10	35	0.1	0.79
Major reasons for admission						
Physical needs	1693	70	16	55	3.1	0.08
Mental health needs	1053	44	17	59	2.6	0.11
Carer needs	878	37	14	48	1.7	0.19
Housing problem	347	14	8	28	4.0	0.05
Lack of motivation	522	21	6	21	0.0	0.9

Table 2.3: Placement and subsequent return to private household

	White		Black & Ethnic Minorities	
	N	*%*	*N*	*%*
Placement	1019	42	15	52
Nursing Home	212	9	0	0
LA Residential Home	1006	42	13	45
Private/Voluntary Residential Home	170	7	1	3
Dual Registered Home				
Returned to private household?	2300	97	26	93
No	81	3	2	7
Yes				

Appendix
Method of Calculating the Age-Standardised Risk Ratio for Admission Rates

The number of expected admissions from individual ethnic groups were calculated from the population figures for England, contained within the OPCS 1991 population census. There was a minor simplification of the admittees' age groups, which involved grouping individuals of 85+ years into one group in order to match the grouping within the population census. The expected numbers of admissions were calculated using the white population as a reference group. The expected admission rate for each ethnic group was calculated as follows:

$$\varepsilon_e = \sum_{agegroups} \frac{P_{e,a}}{P_{w,a}} \cdot A_{w,a}$$

The risk ratio is a simple ratio between the recorded admission rates and the expected admission rates.

$$R_e = \frac{\sum_{agegroups} A_{e,a}}{\varepsilon_e}$$

ε_e - Expected admission rate for each ethnic (e) group.

$A_{w,a}$ - Number of persons in white (w) admissions group within age group, a.

$A_{e,a}$ - Number of persons in ethnic (e) admissions group within age group, a.

$P_{w,a}$ - Number of persons in white (w) census group within age group, a.

$P_{e,a}$ - Number of persons in ethnic (w) census group within age group, a.

R_e - Odds ratio for individual ethnic groups, e. (or for all ethnic groups combined)

The numbers used for these calculations were obtained from the OPCS 1991 Census and are representative of England. They were modified for under-enumeration of ethnic minorities (Simpson, 1996) and are as follows:

Age Group	White		African/Afro-Caribbean		Indian Subcontinent		Chinese	
	$A_{w,a}$	$P_{w,a}$	$A_{e,a}$	$P_{e,a}$	$A_{e,a}$	$P_{e,a}$	$A_{e,a}$	$P_{e,a}$
65-69	81	2,286,002	4	17,192	0	20,008	0	2,084
70-74	215	1,862,700	5	8,624	0	11,667	2	1,330
75-79	389	1,554,357	4	4,214	3	6,245	1	779
80-84	642	1,065,002	0	1,816	1	3,284	3	429
85+	1101	751,026	2	1,115	3	2,283	1	280

Chapter 3
Moves within Residential and Nursing Home Care

3.1 Introduction

The examination of moves within residential and nursing home care is of interest both for welfare and for financial reasons. From a review of the literature on the attitudes and aspirations of older people, Boaz et al. (1999) note that older people who have moved into residential care often identify advantages of their new homes, including the safe environment, the care they received and the company of others, but they also do not want to have to move again. Financially, the move from a residential to a nursing home entails considerable extra costs, with the average weekly fee level for private nursing home care being approximately £100 greater than that for private residential home care (Laing and Buisson, 1999). This chapter presents information from the admissions survey and the three follow-ups up to 30 months on the extent of moving between residential and nursing home care, and reports on the characteristics of movers. For individuals admitted to dual registered homes, moves between residential and nursing beds may be made within the home, thus avoiding unwanted further moves between homes, and this chapter includes information on moves of those admitted to dual registered homes.

Information is presented in this chapter on moves within residential and nursing home care in terms of moves between types of bed and moves between homes. However, since moves between beds were less likely to be underestimated than moves between homes, as explained below, and also incorporated moves within dual registered homes, the analyses concentrate on moves between beds. The information presented in this chapter is based on 2543 cases, following the exclusion of 86 out-of-scope cases, as described in chapter 1. The majority (over 98 per cent) of individuals in the admissions survey were admitted from a domestic household, sheltered housing, residential care, nursing home care, or hospital. The remainder were admitted from an unspecified, 'other' location and, in one case, the information was not recorded. Approximately 13 per cent of the individuals in the admissions survey were admitted from a residential or a nursing home, 10 per cent from a residential home and 3 per cent from a nursing home. For the purposes of the analyses below, the sources of admission have been grouped into four categories, as follows: a private household (including a domestic household, sheltered housing, another location and a missing location); a residential home; a nursing home; and hospital.

3.2 Methodology for Defining Moves

Between the admissions survey and the follow-up of those elderly people who had returned to a private household or who had been discharged to hospital by 30 months, information on the location of the elderly people was obtained on up to 11 occasions, inclusive of the admissions survey and the follow-up. However, the information collected prior to the six month, 18 month and 30 month follow-ups was less detailed than the information collected in the follow-ups themselves. In the admissions survey, individuals were classified according to the type of home (nursing home, residential home, residential bed in a dual registered home, or nursing bed in a dual registered home) and the ownership of the home (local authority, voluntary/not for profit, or private). For those remaining in residential or nursing home care, the information collected in the one month, six month, 18 month and 30 month follow-up studies included the type of bed the resident was occupying and whether the resident was in a different home on the relevant follow-up date. Those who had moved to a different type of home were classified in one of the above four categories, and the same classification was used to record the location of individuals who were recorded as being in residential or nursing home care in the follow-ups of those who had returned to a private household or who had been discharged to hospital. However, the information collected prior to the six month follow-up only covered deaths, while the information collected prior to the 18 month and 30 month follow-ups covered moves to a different home, but did not include the type of home.

For those remaining in residential or nursing home care, moves may have occurred between homes or, in dual registered homes, from one type of bed to another. The questionnaires used for the follow-ups asked respondents to indicate whether the elderly person was in the same home as they were admitted to in the admissions survey, or whether they were in a different home. However, it is possible that some respondents may have not made the connection with the admissions survey and simply recorded that the elderly person was in a residential or nursing bed, thus leading to an underestimate of the number of moves between homes. Consequently, the recording of moves between types of bed, either between homes or, in the case of dual registered homes, within homes, is likely to be more complete than the recording of moves between homes. As noted above, the information collected prior to the 18 month and the 30 month follow-ups recorded moves between homes, but did not identify the type of home. For cases where subsequent follow-up information was obtained, the nature of the move would be clarified, except possibly in the case of moves between the same type of home, and thus the information collected prior to the follow-ups could not be used in determining moves between beds without subsequent follow-up information.

3.3 Destination of Elderly People in the Period up to 30 Month Follow-Up

Tables 3.1 and 3.2 show the destination of individuals in the period up to the 30 month follow-up, according the type of bed that they were admitted to during the admissions survey, and their source of admission. Table 3.1 does not include moves within homes, that is, moves within dual registered homes, and table 3.2 does not include moves between homes to the same type of bed. Table 3.3 summarises the information shown in table 3.2, and table 3.4 shows the same information for those individuals admitted to residential or nursing beds in dual registered homes. Moves out of residential or nursing home care to a private household or hospital are denoted as moves 'elsewhere' in the tables. Table 3.5 shows the time at which moves to a different home or type of bed were recorded. The tables record the moves of individuals prior to death, and details of deaths are given in table 3.6.

As may be seen from tables 3.1 and 3.2, very few individuals left residential or nursing home care after moving to a different home or to a different type of bed. In addition, few individuals were recorded as having returned to residential or nursing home care after having moved to a private household or hospital. However, moves back into the same type of bed following a move out of residential or nursing home care have not been identified separately, and are included in moves 'elsewhere' in table 3.2. Table 3.3 summarises the information shown in table 3.2. In this table, individuals who left residential or nursing home care after moving to a different type of bed are included with those who moved to a different type of bed. Individuals who left residential or nursing home care and then returned are included with those who were just recorded as having left residential or nursing home care.

As may be seen from table 3.3, 6.6 per cent of individuals were recorded as having moved to a different type of bed (7.8 per cent were recorded as having moved to a different home). Individuals admitted to a residential bed were more likely than those admitted to a nursing bed to have moved to a different type of bed (8.5 per cent compared with 4.3 per cent) or to have moved to a different home (9.2 per cent compared with 6.1 per cent).

Table 3.4 shows the corresponding information for individuals admitted to dual registered homes to that shown in table 3.3 for all individuals. Individuals admitted to dual registered homes were less likely to have moved to another home than individuals in the survey as a whole (4.5 per cent compared with 7.8 per cent), but they were more likely to have moved to a different type of bed (14 per cent compared with 6.6 per cent). Among those who moved to a different type of bed, the majority (84 per cent) moved from a residential to a nursing bed. Few of those admitted to a dual registered home moved to a private household or hospital, compared with individuals in the survey as a whole. Including those who had moved to a different home

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or type of bed prior to moving out of residential or nursing home care, 175 individuals (6.9 per cent) were recorded as having moved out of residential or nursing home care. Among those admitted to dual registered homes, seven individuals (3.9 per cent) were recorded as having moved out of residential or nursing home care.

The preceding comparisons relate to the type of bed to which the individual was admitted in the admissions survey. Among those admitted to a residential bed, 11 per cent were admitted from another home, the majority (86 per cent) having been admitted from another residential home. For those admitted to a nursing bed, 16 per cent were admitted from another home, the majority (73 per cent) again having been admitted from a residential home. An estimate of the proportion of individuals admitted to residential care who moved to a nursing bed may be derived by including the 134 individuals admitted to a nursing bed from a residential home with the 1349 individuals admitted to a residential bed from sources other than a nursing home. Among these individuals, 17 per cent were recorded as having moved to a different type of bed, compared with the 8.5 per cent of individuals admitted to a residential bed in the admissions survey who subsequently moved to a different type of bed. Since few individuals in the admissions survey were admitted to a residential bed from a nursing home, the corresponding estimate for individuals admitted to a nursing bed who moved to a residential bed is more similar to the proportion of individuals admitted to a nursing bed in the admissions survey who subsequently moved to a residential bed (6.5 per cent compared with 4.3 per cent).

For individuals who moved to a different type of bed, table 3.5 shows the time at which the move was recorded. The majority of moves (approximately 70 per cent) were recorded at the six month and 18 month follow-ups. Individuals admitted to a nursing bed were more likely to have been recorded as having moved to a different bed at the 18 month follow-up than at the six month follow-up, whereas the corresponding proportions were more similar for individuals admitted to a residential bed.

3.4 Survival of Elderly People in the Period up to the 30 Month Follow-Up

Table 3.6 shows the numbers of individuals who were recorded as having died within 30 months of admission and the number who were recorded as having survived, according to the type of bed that they were admitted to during the admissions survey and their destination, defined in terms of the type of bed they occupied. The percentages given in the table have been calculated after excluding individuals for whom no information was obtained about their destination.

Individuals who were recorded as having moved to a different home or to a different type of bed were more likely to have survived than those who remained in the same home or type of bed, or who left residential or nursing home care. Among those admitted to a residential bed, about 65 per cent of those who moved to a different home or type of bed were recorded as having survived to 30 months following admission, compared with 40 per cent of those who remained in the same home or type of bed. For individuals admitted to a nursing bed, 61 per cent of those who moved to a different home and 73 per cent of those who moved to a different type of bed were recorded as having survived, compared with 20 per cent of those who remained in the same home or type of bed. Although it may be expected that individuals admitted to a nursing bed and moving to residential care would be less frail than those remaining in nursing home care, the greater survival rate among those who moved from a residential bed to nursing home care is unexpected.

The figures shown in table 3.6 include individuals admitted from another home. However, the greater survival rate among those who moved to another home or another type of bed, than among those who remained in the same home or type of bed, was exhibited by individuals admitted from a private household and by those admitted from hospital. Although more complete information about the duration of survival of individuals included in the admissions survey should be available at the end of the study, the greater survival rate among those who moved to a different type of home or bed does not appear to be an artefact.

3.5 Dependency Characteristics of Individuals on Admission according to their Destination

Tables 3.7 and 3.8 present information on the dependency characteristics and cognitive functioning of individuals on admission, according to the type of bed that they were admitted to during the admissions survey and their destination, defined in terms of the type of bed they occupied. The discrepancies between the number of individuals admitted to residential or nursing beds shown in these tables and the total number included in the preceding tables (1369 admissions to residential beds and 1174 admissions to nursing beds) are due to the exclusion of cases with missing dependency or cognitive impairment data. The percentages given in the tables have been calculated after excluding individuals for whom no information was obtained about their destination. The measure of dependency presented in table 3.7 is the Barthel Index of Activities of Daily Living (ADL), which is based on ten functions (Collin et al., 1988). For this index, a higher score (maximum 20) corresponds to a lower level of dependency. The scores on the Barthel Index have been grouped into five categories (0-4, 5-8, 9-12, 13-16, 17-20), following Granger et al. (1979), but with an additional subdivision of the group of higher scores. The measure of cognitive functioning presented in table 3.8 is based on a grouping of

the seven categories of the MDS Cognitive Performance Scale (CPS) (Morris et al., 1994): 'intact' = code 0; 'mild impairment' = codes 1, 2, 3; 'severe impairment' = codes 4, 5, 6.

Individuals admitted to a residential bed who moved to a private household or to hospital had lower levels of dependency than those who remained in residential or nursing home care. Among those who left residential care, 63 per cent had low or very low levels of dependency on admission (Barthel scores 13-20), compared with 52 per cent of those who remained in the same type of bed and 50 per cent of those who moved to a different type of bed. By contrast, individuals admitted to a nursing home and who moved to a different type of bed were more likely to have had low or very low levels of dependency on admission (31 per cent) than those who remained in the same type of bed (11 per cent) or those who left nursing home care (19 per cent). In both cases, there was a statistically significant association between the level of dependency and the destination: for admissions to a residential bed, $X^2 = 18.2$, 8 df, $p = 0.019$; for admissions to a nursing bed, $X^2 = 32.5$, 8 df, $p < 0.001$. For individuals who were admitted to a nursing bed and who remained in residential or nursing home care, there was a significant association between the level of dependency and whether they remained in a nursing bed or moved to a different type of bed ($X^2 = 26.9$, 4 df, $p < 0.001$). However, it should be noted that only 9.2 per cent of individuals admitted to a nursing bed moved from a nursing bed to a different type of bed or left nursing home care, excluding those for whom no information on their destination was obtained.

Individuals admitted to a residential bed who moved to a private household or to hospital also tended to have lower levels of cognitive impairment than those who remained in residential or nursing home care, and the same was the case for individuals admitted to a nursing bed. Among those who left residential care, having been admitted to a residential bed, 82 per cent were cognitively intact or suffered mild cognitive impairment (MDS CPS scores 0-3), compared with 73 per cent of those who remained in the same type of bed and 67 per cent of those who moved to a different type of bed. For those admitted to a nursing bed, 67 per cent of those who left nursing home care were cognitively intact or suffered mild cognitive impairment, compared with 53 per cent of those who remained in the same type of bed and 50 per cent of those who moved to a different type of bed. However, the association between the level of cognitive impairment and the destination was not statistically significant in either case: for admissions to a residential bed, $X^2 = 7.09$, 4 df, $p = 0.131$; for admissions to a nursing bed, $X^2 = 7.71$, 4 df, $p = 0.103$.

The preceding comparisons relate to the type of bed to which the individual was admitted in the admissions survey. Although 50 per cent of those who moved from a residential bed to a different type of bed had low or very low levels of dependency on admission to residential care,

and 67 per cent were cognitively intact or suffered mild cognitive impairment, individuals admitted to a nursing bed from a residential home had higher levels of dependency and cognitive impairment on admission. Only 18 per cent of these individuals had low or very low levels of dependency and 46 per cent were cognitively intact or suffered mild cognitive impairment. As noted above, individuals admitted to a nursing bed who moved to a different type of bed had lower levels of dependency than those who remained in the same type of bed or who left nursing home care. Among these individuals, 31 per cent had low or very low levels of dependency on admission and 50 per cent were cognitively intact or suffered mild cognitive impairment. However, 50 per cent of those individuals who were admitted to a residential bed from a nursing home had low or very levels of dependency and 80 per cent were cognitively intact or suffered mild cognitive impairment, although, as noted above, few individuals were admitted to a residential bed from a nursing home.

As explained in section 3.3, above, an estimate of the proportion of individuals admitted to residential care who moved to a nursing bed may be derived by including the individuals admitted to a nursing bed from a residential home with those individuals admitted to a residential bed from sources other than a nursing home, and a similar estimate may be made of the proportion of individuals admitted to nursing home care who moved to a residential bed. Among the individuals admitted to a nursing bed from a residential home or who were admitted to a residential bed from sources other than a nursing home, and who subsequently moved to a different type of bed, 34 per cent had low or very low levels of dependency on admission and 56 per cent were cognitively intact or suffered mild cognitive impairment. Among those who were admitted to a residential bed and who moved to a different type of bed, 50 per cent had low or very low levels of dependency on admission and 67 per cent were cognitively intact or suffered mild cognitive impairment. For individuals admitted to a residential bed from a nursing home or who were admitted to a nursing bed from sources other than a residential home, and who subsequently moved to a different type of bed, 35 per cent had low or very low levels of dependency on admission and 60 per cent were cognitively intact or suffered mild cognitive impairment. The proportion of individuals with low or very low levels of dependency on admission is similar to that for those who were admitted to a nursing bed and who moved to a different type of bed (31 per cent), whereas the proportion who were cognitively intact or who suffered mild cognitive impairment is somewhat higher than that for those who were admitted to a nursing bed and who moved to a different type of bed (50 per cent). However, few individuals were admitted to a residential bed from a nursing home.

Information on the dependency of individuals who were admitted to a nursing bed from a residential home or to a residential bed from a nursing home was obtained at the time of the re-admission. Thus, combining information on dependency for those admitted to residential or

nursing home care for the first time in the admissions survey with that for those who were admitted from another home does not take account of changes in levels of dependency between the original admission and the re-admission. However, incorporating information for those admitted from another home does alter the levels of dependency in the expected direction for both admissions to residential and nursing home care, although the difference is more marked for those who moved from residential to nursing home care since the majority of moves between residential and nursing homes were in this direction.

As noted above, moves out of residential and nursing home care include moves to a private household or to hospital, and it may be expected that individuals who moved to a private household were less dependent than those who moved to hospital. In fact, individuals who moved to a private household or to hospital had similar distributions of levels of dependency on admission, particularly those admitted to a residential bed. Among those admitted to a residential bed, 63 per cent of both those who moved to a private household and those who moved to hospital had low or very low levels of dependency on admission. Among those admitted to a nursing bed, a slightly higher proportion of those who moved to a private household had low or very low levels of dependency, compared with those who moved to hospital, but there were only a few of these individuals. Ideally, comparisons of levels of dependency of those who moved to different locations should be based on the level of dependency at the time of the move, not the level of dependency on admission. As reported in chapter 4, information on dependency levels at the time of the move was obtained for about two-thirds of those who moved to a private household, but those who moved to hospital were not routinely followed up.

3.6 Predicted Location of Individuals and their Destination

In a previous paper (Netten et al., 1999), logistic regression analysis was used to compare the characteristics of individuals admitted to a nursing home bed with the characteristics of those who were admitted to a residential bed. The variables examined in the analysis related to personal characteristics (age group, sex, Barthel score, cognitive impairment, problem behaviour, need for nursing care, disorders and diseases, and reasons for admission), household composition and source of admission. A model including variables which reached the 5 per cent level of statistical significance produced correct predictions of the type of bed to which the individual was admitted for over 81 per cent of cases. Since 54 per cent of the sample had been admitted to a residential bed and 46 per cent had been admitted to a nursing bed, the minimum proportion of correct predictions, 54 per cent, could be achieved by allocating all cases to residential beds. Thus the model provided a substantial improvement over this. The variables

included in the final equation were: the (grouped) Barthel score; the frequency of problem behaviour; whether the individual suffered from malignancy, whether they suffered from arthritis; whether they suffered from deafness; whether they required daily dressings; whether they required bedfast procedures; whether they required other nursing care; whether their admission was due to physical health problems; whether their admission was due to family breakdown; whether their admission was due to a lack of motivation; whether they lived alone or with others; and their source of admission. Individuals who suffered from arthritis or deafness, or whose admission was due to family breakdown or a lack of motivation, or who lived alone, were more likely to be admitted to a residential bed.

Table 3.9 shows the predicted location of individuals based on the logistic regression model, according to the type of bed that they were admitted to during the admissions survey and their destination, defined in terms of the type of bed they occupied. Individuals who were recorded as having assets exceeding the capital limit for public funding (£8000 at the time of the survey) were not included in the logistic regression analysis, and are excluded from the table. Individuals with a predicted probability of less than 0.5 of being admitted to a nursing bed have been predicted to be admissions to a residential bed, and individuals with a predicted probability of at least 0.5 of being admitted to a nursing bed have been predicted to be admissions to a nursing bed. Predictions cannot be made for individuals with missing information for one or more of the variables in the logistic regression equation, and these individuals have been omitted from the table. The percentages given in the table have been calculated after excluding individuals for whom no information was obtained about their destination.

The logistic regression model predicted that 87 per cent of those admitted to a residential bed would have been admitted to a residential bed and that 75 per cent of those admitted to a nursing bed would have been admitted to a nursing bed. Individuals admitted to a residential bed and who moved to a nursing bed were slightly more likely to have been predicted to have been admitted to a nursing bed than those who remained in a residential bed (18 per cent compared with 13 per cent). However, the association between the predicted location and the destination was not statistically significant ($X^2 = 1.95$, 1 df, $p = 0.163$). In contrast, individuals admitted to a nursing bed and who moved to a residential bed were substantially more likely to have been predicted to have been admitted to a residential bed than those who remained in a nursing bed (60 per cent compared with 23 per cent), a statistically significant association ($X^2 = 27.3$, 1df, $p < 0.001$). However, it should be noted that the number who moved from a nursing bed to a residential bed was relatively small.

The source of admission was included as a predictor in the logistic regression model, and so it is not necessary for this analysis to adjust the number of individuals admitted to residential or nursing home care to take account of those admitted from another home.

3.7 Conclusions

Approximately 8 per cent of the individuals included in the admissions survey were recorded as having moved to a different home and 6.6 per cent were recorded as having moved to a different type of bed. Individuals admitted to a residential bed were more likely than those admitted to a nursing bed to have moved to a different home or to a different type of bed. Individuals admitted to dual registered homes were less likely to have moved to another home but more likely to have moved to a different type of bed than individuals in the survey as a whole, and the majority moved from a residential to a nursing bed.

Including individuals who were admitted to a nursing bed from a residential home suggests that approximately 17 per cent of individuals admitted to a residential bed subsequently move to a different type of bed. It should be noted, however, that this figure does not include moves from a residential bed via hospital and moves later than 30 months after admission.

Individuals who moved to a different home or type of bed were more likely to have survived to the 30 month follow-up than those who remained in the same home or type of bed, an unexpected finding for those who moved from a residential bed to a nursing bed.

Individuals who moved from a nursing bed to a residential bed had lower levels of dependency on admission than those who remained in the same type of bed or who left nursing home care. Individuals who moved from a residential bed to a nursing bed had similar levels of dependency on admission to those who remained in the same type of bed. Individuals admitted to a residential bed who moved to a private household or to hospital had lower levels of dependency than those who remained in residential or nursing home care.

Predictions of the type of bed that individuals would be expected to have been admitted to, derived from a logistic regression analysis, have been compared with moves between residential and nursing home care. This showed that individuals who moved to a different type of bed were more likely to have been predicted to be admitted to that type of bed than those who remained in the original type of bed. The association between the predicted location and the destination was much weaker for those admitted to a residential bed than for those admitted to a nursing bed. The results suggest that the limited moves from nursing to residential beds are

likely to result from initial misplacement. The moves from residential to nursing beds, on the other hand, are less evident from characteristics on admission, suggesting that changes in health state are more likely to be the factors precipitating a move. Chapter 6 discusses changes in health state generally. Further analyses will explore the links between these factors and moves between residential and nursing home care.

Table 3.1: Destination (type of home) of individuals in period to 30 month follow-up, by type of bed admitted to and source of admission (number of cases)

Type of bed admitted to and source of admission	Same home that admitted to	Different home	Different home then elsewhere	Elsewhere	Elsewhere then returned to a home	No information	All individuals
Number of individuals	1958	188	10	130	35	222	2543
Admitted to residential bed	991	119	7	91	28	133	1369
From private household	455	66	2	38	22	55	638
From residential home	98	13	2	4	0	10	127
From nursing home	15	1	0	1	0	3	20
From hospital	423	39	3	48	6	65	584
Admitted to nursing bed	967	69	3	39	7	89	1174
From private household	203	14	1	7	4	20	249
From residential home	111	7	1	2	0	13	134
From nursing home	42	3	0	1	0	3	49
From hospital	611	45	1	29	3	53	742

Table 3.2: Destination (type of bed) of individuals in period to 30 month follow-up, by type of bed admitted to and source of admission (number of cases)

Type of bed admitted to and source of admission	Same type of bed that admitted to	Different type of bed	Different type of bed then elsewhere	Elsewhere	Elsewhere then different type of bed	No information	All individuals
Number of individuals	1978	162	5	154	16	228	2543
Admitted to residential bed	994	112	4	109	13	137	1369
From private household	455	65	1	51	10	56	638
From residential home	99	11	1	5	0	11	127
From nursing home	14	1	0	1	0	4	20
From hospital	426	35	2	52	3	66	584
Admitted to nursing bed	984	50	1	45	3	91	1174
From private household	203	14	1	9	2	20	249
From residential home	115	2	0	3	0	14	134
From nursing home	44	1	0	1	0	3	49
From hospital	622	33	0	32	1	54	742

Table 3.3: Destination (type of bed) of individuals in period to 30 month follow-up, by type of bed admitted to and source of admission

Type of bed admitted to and source of admission	Same type of bed that admitted to		Different type of bed		Elsewhere		No information		All individuals	
	No.	%	No.	%	No.	%	No.	%	No.	%
Number of individuals	1978	77.8	167	6.6	170	6.7	228	9.0	2543	100.0
Admitted to residential bed	994	72.6	116	8.5	122	8.9	137	10.0	1369	100.0
From private household	455	71.3	66	10.3	61	9.6	56	8.8	638	100.0
From residential home	99	78.0	12	9.4	5	3.9	11	8.7	127	100.0
From nursing home	14	70.0	1	5.0	1	5.0	4	20.0	20	100.0
From hospital	426	72.9	37	6.3	55	9.4	66	11.3	584	100.0
Admitted to nursing bed	984	83.8	51	4.3	48	4.1	91	7.8	1174	100.0
From private household	203	81.5	15	6.0	11	4.4	20	8.0	249	100.0
From residential home	115	85.8	2	1.5	3	2.2	14	10.4	134	100.0
From nursing home	44	89.8	1	2.0	1	2.0	3	6.1	49	100.0
From hospital	622	83.8	33	4.4	33	4.4	54	7.3	742	100.0

Table 3.4: Destination (type of bed) of individuals admitted to dual registered homes in period to 30 month follow-up, by type of bed admitted to and source of admission

Type of bed admitted to and source of admission	Same type of bed that admitted to		Different type of bed		Elsewhere		No information		All individuals	
	No.	%	No.	%	No.	%	No.	%	No.	%
Number of individuals	125	70.2	25	14.0	7	3.9	21	11.8	178	100.0
Admitted to residential bed	56	59.6	21	22.3	4	4.3	13	13.8	94	100.0
From private household	25	56.8	12	27.3	2	4.5	5	11.4	44	100.0
From residential home	3	50.0	1	16.7	0	0.0	2	33.3	6	100.0
From nursing home	3	60.0	1	20.0	0	0.0	1	20.0	5	100.0
From hospital	25	64.1	7	17.9	2	5.1	5	12.8	39	100.0
Admitted to nursing bed	69	82.1	4	4.8	3	3.6	8	9.5	84	100.0
From private household	8	66.7	3	25.0	0	0.0	1	8.3	12	100.0
From residential home	10	76.9	0	0.0	0	0.0	3	23.1	13	100.0
From nursing home	2	100.0	0	0.0	0	0.0	0	0.0	2	100.0
From hospital	49	86.0	1	1.8	3	5.3	4	7.0	57	100.0

Table 3.5: Time of move of individuals who moved to a different type of bed in period to 30 month follow-up, by type of bed admitted to and source of admission

Type of bed admitted to and source of admission	1 month		6 months		18 months		30 months		All individuals	
	No.	%	No.	%	No.	%	No.	%	No.	%
Number of individuals	10	6.0	49	29.3	71	42.5	37	22.2	167	100.0
Admitted to residential bed	9	7.8	38	32.8	42	36.2	27	23.3	116	100.0
From private household	4	6.1	19	28.8	25	37.9	18	27.3	66	100.0
From residential home	0	0.0	5	41.7	5	41.7	2	16.7	12	100.0
From nursing home	0	0.0	0	0.0	0	0.0	1	100.0	1	100.0
From hospital	5	13.5	14	37.8	12	32.4	6	16.2	37	100.0
Admitted to nursing bed	1	2.0	11	21.6	29	56.9	10	19.6	51	100.0
From private household	0	0.0	3	20.0	9	60.0	3	20.0	15	100.0
From residential home	0	0.0	0	0.0	1	50.0	1	50.0	2	100.0
From nursing home	0	0.0	0	0.0	0	0.0	1	100.0	1	100.0
From hospital	1	3.0	8	24.2	19	57.6	5	15.2	33	100.0

Table 3.6: Survival of individuals in 30 months following admission, by destination (type of bed)

Type of bed admitted to and survival to 30 months	Same type of bed that admitted to		Different type of bed		Elsewhere		No information		All individuals	
	No.	%	No.	%	No.	%	No.	%	No.	%
Number of individuals	1978	85.4	167	7.2	170	7.3	228	-	2543	100.0
Admitted to residential bed	994	80.7	116	9.4	122	9.9	137	-	1369	100.0
Not recorded died within 30 months	393	76.3	75	14.6	47	9.1	137	-	652	100.0
Died within 30 months	601	83.8	41	5.7	75	10.5	0	-	717	100.0
Admitted to nursing bed	984	90.9	51	4.7	48	4.4	91	-	1174	100.0
Not recorded died within 30 months	194	78.2	37	14.9	17	6.9	91	-	339	100.0
Died within 30 months	790	94.6	14	1.7	31	3.7	0	-	835	100.0

Table 3.7: Destination (type of bed) of individuals in period to 30 month follow-up, by type of bed admitted to and dependency (Barthel Index of ADL) at admission

Type of bed admitted to and dependency at admission	Same type of bed that admitted to		Different type of bed		Elsewhere		No information		All individuals	
	No.	%	No.	%	No.	%	No.	%	No.	%
Number of individuals	1974	77.7	167	6.6	170	6.7	228	-	2539	100.0
Admitted to residential bed	944	80.7	116	9.4	122	9.9	137	-	1369	100.0
Very low dependence (Score 17-20)	196	76.0	20	7.8	42	16.3	33	-	291	100.0
Low dependence (Score 13-16)	297	80.3	38	10.3	35	9.5	46	-	416	100.0
Moderate dependence (Score 9-12)	299	83.1	32	8.9	29	8.1	30	-	390	100.0
Severe dependence (Score 5-8)	154	82.4	19	10.2	14	7.5	26	-	213	100.0
Total dependence (Score 0-4)	48	84.2	7	12.3	2	3.5	2	-	59	100.0
Admitted to nursing bed	980	90.8	51	4.7	48	4.4	91	-	1170	100.0
Very low dependence (Score 17-20)	30	83.3	4	11.1	2	5.6	5	-	41	100.0
Low dependence (Score 13-16)	80	80.8	12	12.1	7	7.1	10	-	109	100.0
Moderate dependence (Score 9-12)	187	89.5	11	5.3	11	5.3	11	-	220	100.0
Severe dependence (Score 5-8)	318	92.2	19	5.5	8	2.3	31	-	376	100.0
Total dependence (Score 0-4)	365	93.6	5	1.3	20	5.1	34	-	424	100.0

Table 3.8: Destination (type of bed) of individuals in period to 30 month follow-up, by type of bed admitted to and cognitive impairment (MDS Cognitive Performance Scale) at admission

Type of bed admitted to and cognitive impairment at admission	Same type of bed that admitted to		Different type of bed		Elsewhere		No information		All individuals	
	No.	%	No.	%	No.	%	No.	%	No.	%
Number of individuals	1859	85.6	151	7.0	161	7.4	211	-	2382	100.0
Admitted to residential bed	962	81.0	107	9.0	118	9.9	130	-	1317	100.0
Intact (Score 0)	196	79.7	22	8.9	28	11.4	39	-	285	100.0
Mild impairment (Score 1-3)	504	80.9	50	8.0	69	11.1	64	-	687	100.0
Severe impairment (Score 4-6)	262	82.4	35	11.1	21	6.6	27	-	345	100.0
Admitted to nursing bed	897	91.2	44	4.5	43	4.4	81	-	1065	100.0
Intact (Score 0)	153	87.4	8	4.6	14	8.0	18	-	193	100.0
Mild impairment (Score 1-3)	326	91.8	14	3.9	15	4.2	31	-	386	100.0
Severe impairment (Score 4-6)	418	92.1	22	4.8	14	3.1	32	-	486	100.0

Table 3.9: Destination (type of bed) of individuals in period to 30 month follow-up, by type of bed admitted to and type of bed predicted from logistic regression model[1]

Type of bed admitted to and type of bed predicted	Same type of bed that admitted to		Different type of bed		Elsewhere		No information		All individuals[2]	
	No.	%	No.	%	No.	%	No.	%	No.	%
Number of individuals	1781	85.6	146	7.0	154	7.4	201	-	2282	100.0
Admitted to residential bed	921	80.9	106	9.3	111	9.8	124	-	1262	100.0
Predicted residential bed	801	81.3	87	8.8	97	9.8	109	-	1094	100.0
Predicted nursing bed	120	78.4	19	12.4	14	9.2	15	-	168	100.0
Admitted to nursing bed	860	91.2	40	4.2	43	4.6	77	-	1020	100.0
Predicted nursing bed	659	93.6	16	2.3	29	4.1	56	-	760	100.0
Predicted residential bed	201	84.1	24	10.0	14	5.9	21	-	260	100.0

Notes: 1. See Netten et al. (1999).
2. Excluding individuals with assets exceeding £8000.

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Chapter 4
People who leave Residential and Nursing Home Care

4.1 Introduction

Modernising Social Services (Cm 4169) argued that residential care services are sometimes used inappropriately for people who would be better provided with rehabilitation services following hospital discharge (§2.8) and that there was a failure to review (§2.11) which meant that alternatives were never subsequently considered. Indeed, it has been suggested that even after the Community Care reforms, local authorities have still had perverse incentives to provide residential and nursing care rather than intensive domiciliary care because of the proportion of costs that can be recovered through charges and Residential Allowance.

The previous chapter described the degree to which people move after initially being admitted to a care home. This chapter examines the circumstances surrounding people who actually left residential and nursing home care, particularly those returning back to the community. A wide variety of issues are raised by such moves, some of which can be addressed in the context of this survey. While it is not possible to get a detailed picture of the type of care provided we can investigate a number of factors. These include:
- the reasons given for the move,
- whether people appeared to recover sufficiently to enable them to return to the community,
- what happened to them after they had left the home,
- what levels of support they receive in the community,
- whether they soon return to a care home and
- their outcome in terms of health and survival.

4.2 Reports of Moves

Among the 2543 people aged 65+ who were admitted long-term, or at least for an indefinite period, we have identified a total of 182 (7.2 per cent) who were identified as having been permanently discharged at some time up to 30 months after admission[2]. This includes people who subsequently returned to a care home and seven who died on the day of discharge.

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[2] A total of 201 were reported as having moved from the home, but on tracking several were found not to have done so, at least for a significant period.

These individuals were identified usually through replies from heads of homes at each of the one, 6, 18 and 30 month follow-ups to an initial question on the postal survey. Candidates for tracking at the 6, 18 and 30 month follow-ups were those people who had been discharged, other than to another care home, and were not known to be dead. Those that were known to have been discharged to a hospital were not in general tracked, other than to establish date of death. Those who were discharged back to private households were followed up wherever possible through the social worker or care manager responsible. Contact was not normally made directly with the client. Some cases where the place of discharge was uncertain were also tracked. Once tracking was started, it was repeated at subsequent waves of the survey unless the person was reported to have died or returned to a care home, in which case they would return to the main survey. In total a track was attempted for 162 people at some stage of whom 134 proved to be valid cases (i.e. among the 182 described above) and 104 were still alive when the track was completed. Thirty-eight of these were successfully tracked at more than one stage.

There is an issue about whether this reflects the full extent of moves. In fact it might be an over-estimate.

- The tracking did reveal that a few people were incorrectly reported as having left the home, though the number is small.
- Quite a number of those described as being discharged to hospital in fact died within a few days, and perhaps should not have been classed as having been discharged to a permanent place elsewhere.
- Some of those discharged in the early months we discovered had been regarded by their care managers as short term cases, even though they entered the care home for an indefinite period (our definition of a 'long-stay admission').

On the other hand at 30 months we were unable to trace 9 per cent of the original admissions sample (i.e. no report at this stage, and not previously reported as having died). Some of these people had been lost through previous rounds. We must assume that the discharge rate for this group was at least as great as among those who were recontacted, which would mean slightly more people were discharged than we identified. It might even be that the discharge rate is higher among this group. However, the main reason for failure of contact is no reply from the head of home, which is not necessarily indicative that the resident has moved away.

4.3 Removal Rates

The preceding section shows that exact discharge rate is partly a matter of definition, but however defined, it is quite small, indeed smaller than many professionals have believed. Of the 182 cases identified in the survey, 88 went to live in a private household while 94 were dicharged to hospital.

It is of interest to ask how long it was before residents were discharged. However, although we know where all of them went, the date of (first) removal is not known precisely in 38 cases. This is not quite as bad as it sounds because date of move can be partially inferred from the time at which the person was last reported being in a care home and the time at which the move was first reported, and there is sometimes other ancillary evidence to help pinpoint the time. The analysis that follows only requires removal time accurate to 3 months. For these missing cases, we have imputed a date of move based on the information available[3].

With these imputations it is possible to use survival analysis to establish discharge rates through time. It does however assume that missing cases do not behave differently from those who we have traced. Table 4.1 uses a life-table approach that will allow for people lost to competing risks (i.e. death, being lost to the study, discharged elsewhere). This allows computation of the hazard rate, the probability of being discharged in a month, given survival up to that month.

The probability of leaving a care home in the first 30 months after admission as a long-term elderly resident is low, at 10.0 per cent (from tables 4.1A and 4.1B combined). On this basis the 'lifetime' probability of discharge is approximately 11.0 percent, assuming hazard rates for discharge continue beyond 30 months at the level they were in the period 18-30 months.

Most moves take place fairly soon after admission. The pattern is a little different between moves to a private household and moves to a hospital. For the former group the rate of removal drops off quickly after the first few months, and after 12 months only a trickle return to the community. On the other hand, there are still a few moves to hospital up to the 30 month limit.

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[3] The method uses a date picked at random between the two dates for which information is available. For moves after 6 months a uniform distribution is used. Prior to 6 months, the distribution of the random date is adjusted to reflect the bias towards early removals based on those people for whom information is available. One third of the missing cases moved out in the first 6 months, the others between 6 and 30 months.

4.4 Why do People return to Private Households?

The low incidence of discharges might suggest that on the whole either placements were appropriate or that changes in living situation were not made in response to changes in need.

Reasons for the move have been given in about half the 104 cases where a track was successful (table 4.2A). The nature of institutional care was found to be unacceptable by a large proportion of the people who returned to the community. The most common reason given for the move was that the elderly person 'did not settle', some aspects of care such the loss of autonomy and the lack of privacy being cited as a factors. The second most common reason given by their social workers for the elderly person's return to the community was that their health status or functioning had improved (24 per cent). An additional 11 per cent of all cases stated that rehabilitation had been successfully completed, indicating that in at least these cases a planned programme to facilitate a return home. These qualitative judgements can be supported by detailed examination of the objective evidence.

4.4.1 Appropriateness of placement

The majority of people who were discharged to private households had been admitted to residential care, which probably reflects the lower dependency of people in those establishments. Nevertheless, 30 per cent had been to nursing care.

Is there anything about the people who returned that might suggest that the placement was not really appropriate in the first place? We can draw some conclusions by examining the circumstances on admission of people who left institutional care to return to living in the community. Table 4.3 shows that they were slightly younger than average and were more likely to have been admitted from a private household. However, they were not people who were particularly likely to have left a partner in the community who could take up their support again. Sixty per cent had been living alone prior to admission, a similar proportion to that for all admissions.

The most striking characteristic of those returning to live in a private household was their relatively low level of dependency at the time of the original admission. More than a quarter were rated as highly independent on the Barthel scale used in the survey. The levels of confusion of people returning to the community were also lower overall. Thirty-five per cent were cognitively intact on admission and only 14 per cent were severely impaired compared with 35 per cent of all admissions.

Table 4.3 also indicates that housing problems and social isolation were mentioned more frequently as reasons for admission by those who subsequently left. Put together, this might well suggest that some of those who subsequently returned to the community from placement in residential or nursing home care did not really need this form of care in the long term..

4.4.2 Recovery

Improvement in health was given as a reason for their leaving care in one quarter of cases (table 4.2A). This is supported by the evidence of changes in dependency between admission and follow up after discharge to the community (see table 4.4). One third of cases with dependency information at follow-up, showed an improvement of four or more points on the Barthel scale, which is considered a significant measure of improvement (Collin et al., 1988). Typically these were people with a low initial score, whereas those that did not improve were mostly fairly high on the Barthel score to start with. Thus at discharge, the great majority were fairly able on the Barthel scale.

A similar story emerges from looking at survivors at 30 months. Of the 21 leavers for whom health status was obtained at 30 months, 15 (71 per cent) scored the same or better on the Barthel score than they had on admission. By comparison, only one third of those still alive in care homes were no worse in terms of their Barthel score. Further evidence that recovery was a factor in discharge is that subsequent survival rates of people discharged were better, even allowing for health differences at the time of admission (see §4.5.4).

4.4.3 Rehabilitation

Although rehabilitation became a major theme following *Modernising Social Services,* even at the time of the admissions survey it was seen as a significant role for care homes. In six per cent of all cases one of the main reasons for admission was stated to be the need for rehabilitation. Compare this with the three per cent who actually did return to a private household. Of the 134 for whom rehabilitation was given as a reason for admission, only 14 (10 per cent) actually did return.

Rehabilitation as a reason for admission varied greatly between local authorities. In one authority 16 per cent of all admissions were said to be for rehabilitation, while in others there were no cases. The former authority, a metropolitan borough, was also to become the one with the highest rate of discharges to the community (11 per cent of its admissions). This borough had a positive policy of admitting elderly people to homes specifically for the purposes of rehabilitation and convalescence and had a history of good partnership with the health authority.

Discharges to the community were particularly rare in London. Only two out of 262 London admissions returned to private households. There may be particular barriers at work here, perhaps related to out of borough placements, admission policies or practice issues.

4.4.4 Availability of alternatives

Table 4.2 shows that in only one case was the person reported as being able to return to a private household because a carer was again available, though as we note below, there were probably more. There were a couple of cases where residents were able to return to the community because their housing difficulties had been resolved, by providing them with sheltered accommodation.

4.5 What Happens following Return to the Community?

4.5.1. Living circumstances

Eighty-eight cases were known to have been discharged to a private household. Social services had lost contact with 12 of these. Of the remaining 76 cases, social services case workers provided information on 41, and we know most about these.

They fall into two distinct groups. Eighteen of these 41 returned to the community to live in a household with another person or persons. These people had mostly been highly dependent at the time of admission, two thirds being rated as severely or totally dependent on the Barthel Index (scores 0-8), and one third were severely cognitively impaired. Typically they had made some improvement while in the home so that after discharge the Barthel scores for half of them had improved by more than four points. For the most part they were able to return to the community because there was informal support there for them.

The larger group of 23 returned to live alone. Nearly three-quarters of this group had been of low or very low dependence on admission (Barthel scores 12-20), and half of them were cognitively intact (compared with 20 per cent of all admissions).

4.5.2. Continued social services involvement

Of the 41 in touch with a case worker, 34 were in receipt of services and nine were not. We must assume however that the level of involvement was less in the cases where there was no contact. So it is likely that at least one-quarter and perhaps many more did not receive support from social services in the long term after discharge.

However those who did receive services often got a lot. The extreme was one case reported to be allocated five hours of home help and four community nurse visits per day, but this was probably for just a short period. Table 4.5 shows the average amount of services received. It did not seem to matter whether or not the person was returning to live alone. Possibly this was because those returning to live with others were more dependent and had a need for respite care.

Of the nine who received no services, five lived alone and four with others.

4.5.3 Return to a care home

Of the 88 who were discharged, 15 had returned to a care home by 30 months, or before they died. Often the return was quite quick. Only six of these had remained in the private household for three months or more.

4.5.4 Survival

Because case managers were not in daily contact with their clients, reported dates of death might be a little less accurate than for those living in care homes. However, it is evident, and not surprising in view of their better health, that people who return to private households survive longer than average. Of the 88 who were discharged, at 30 months 41 had died, 33 were alive and the status of 14 was unknown. This includes people who subsequently returned to a care home. Their median survival is estimated as 26 months, compared with 18 months for the remainder of the admissions group[4]. Even if we allow for the circumstances at admission, using the statistical model given in table 4.4, it is still the case that leavers survive better. The odds that they die in any given month is only one half that of people who never leave. This is further evidence of the link between health improvement and subsequent discharge.

Most people survived reasonably well after being discharged, as one might expect if recovery was a factor. Only two are known to have died within a month of leaving. In both cases it is believed that these were people who were enabled to return home for terminal care.

4.6 People Discharged to Hospital Care

Ninety-four people were identified as having been permanently discharged to hospital. As noted in § 4.2, we were concerned to distinguish those who were admitted for a short period

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[4] Though this may be a slight overestimate because a suspicious number of dates of death were given as very close to the date that the care managers were reinterviewed, and may be therefore have been reported as when the care manager checked rather than the actual date of death.

prior to death from those for whom the move was 'permanent', but it obvious that the distinction is a fine one. Only 53 of those discharged to hospital are known to have survived for more than two weeks subsequently (with another 9 'not certain'), and the assumption must be that many of the remainder were discharged with immediate terminal care needs.

Table 4.1B shows that the majority of discharges to hospital took place quite shortly after admission. This might imply one of two things. First, that the admission to a care home was inappropriate, it "should have been realised" that the person would shortly need full-time hospital care, and the stress and expense of a double relocation avoided. Second, that after someone has been in a care home for a while, an effort is made to help them avoid going into permanent hospital care, for example by providing terminal care in the home, or by keeping their bed open for them even when they do.

We do not know a great deal about why people were discharged to hospital care, because these cases were not routinely followed up. However from 26 that were, not surprisingly illness is the main reason, though perhaps less expected are the cases referred to hospital because of increased dependency or behaviour problems (table 4.2B).

Based on their circumstances at admission, it would not have been easy to predict who would be discharged to hospital care (table 4.3). Surprisingly these people were actually less dependent than average on admission. Their health was no worse, except they are slightly more likely to have been diagnosed with dementia prior to admission. Men are more likely to be discharged to hospital than women.

Therefore we cannot say that there was obvious evidence of misplacement of those who were subsequently moved into hospital care. However, it is worth noting that there were considerable differences in the incidence of such discharges in different local authorities, which may have been the consequence of a range of different local pressures. Whereas the overall rate of discharge to hospital was four cent of all admissions, across the participating local authorities this ranged from two per cent to nine per cent of their admissions.

Survival following discharge to hospital was rarely long. Even for those people who survived the first two weeks, the median is under three months. However 10 people eventually returned to a care home, and 13 survived for a year or more in a long-stay hospital bed.

4.7 Conclusions

The most striking observation is just how few people actually ever leave a care home environment once admitted. The great majority of those that do, leave fairly soon after admission. Thereafter there would seem to be an effort made to retain the resident in the home wherever possible. We cannot conclude on the basis of subsequent moves that there is much evidence of misplacement at admission.

If this means that eventually there are people in residential care with the same level of disabilities and ill-health as is associated with admissions to nursing care, this gives rise to the question of what real difference there is between the two sectors. This question will be returned to in other chapters.

Though failure to settle was given as the commonest reason for discharge back to private households, it is evident that the majority of such people had been admitted at low levels of dependence and the health of others had improved. Though informal care is often a factor enabling discharge, a significant number returned to live alone (possibly in sheltered housing). This group had better survival prospects than those remaining in a care home.

Rehabilitation was considered for 6 per cent of people at the time of admission, but rarely happened for them. Only a few of the people who were actually discharged to a private household had been admitted with rehabilitation in mind. Nevertheless, those local authorities that were most minded to consider rehabilitation, did indeed discharge the most cases, even if they were not the ones originally planned.

Discharge to hospital usually means for terminal care, and many die soon after. But a few people seem to have lived in a long stay in hospital for a long time afterwards, or been subsequently readmitted to a care home. While discharge to a hospital is normally the result of illness, in a few cases it is because of problems associated with disability or dementia.

Table 4.1: Discharge rates from care homes

(A) People discharged to private households

Interval (months from admission)	Number at start	Number lost in interval	Average number "at risk"	Number discharged to private households	Proportion discharged %	Monthly hazard rate (with s.e.) %
0-3	2543	564	2261	50	2.2	0.75 (0.10)
3-6	1929	207	1825½	14	0.8	0.25 (0.07)
6-12	1708	320	1548	17	1.1	0.18 (0.05)
12-18	1371	228	1257	3	0.2	0.04 (0.02)
18-24	1140	280	1000	2	0.2	0.03 (0.02)
24-30	858	159	778½	2	0.3	0.04 (0.03)
30+	697					

(B) People discharged to hospital

Interval (months from admission)	Number at start	Number lost in interval	Average number "at risk"	Number discharged to hospital	Proportion discharged %	Monthly hazard rate (with s.e.) %
0-3	2543	569	2258½	45	2.0	0.67 (0.10)
3-6	1929	203	1827½	18	1.0	0.33 (0.08)
6-12	1708	327	1544½	10	0.7	0.11 (0.03)
12-18	1371	219	1261½	12	1.0	0.16 (0.05)
18-24	1140	280	1000	2	0.2	0.03 (0.02)
24-30	858	154	781	7	0.9	0.15 (0.06)
30+	697					

Table 4.2: Principal reasons for discharge

(A) People discharged to private households

	No.	*%*
Client did not settle	16	43
wanted to be in own home	*10*	*27*
wanted to be with partner	*3*	*8*
did not like sharing/lack of privacy	*3*	*8*
found other residents too confused	*1*	*3*
Physical condition improved	9	24
Rehabilitation successfully completed	4	11
Carer able to resume caring	1	3
Other	7	19

Based on 37 people providing reasons

(B) People discharged to hospitals

	No.	*%*
Illness/needed hospital care	10	36
Increase in dependency	6	21
loss of mobility	*4*	*14*
became incontinent	*2*	*7*
confusion increased	*1*	*4*
Home could not cope with aggressive	3	11
behaviour	1	4
Other	8	27
Not known		

Based on 28 people providing reasons

Table 4.3: Characteristics on admission of people who moved out of residential or nursing home care within 30 months of admission

	Moved to private household n=88	Moved to hospital n=94	All Admissions n=2543
	%	%	%
Gender			
Male	26	36	29
Female	74	64	71
Age group			
65-69	6	5	3
70-74	15	17	9
75-79	23	10	17
80-84	19	35	26
85+	38	33	45
Household composition			
Lived alone	60	71	64
Lived with others	40	29	36
Admitted from			
Hospital	43	51	52
Community	50	39	34
Other	7	10	14
Barthel score			
Very low dependence (score 17-20)	27	22	13
Low dependence (score 13-17)	24	28	21
Moderate dependence (score 9-12)	21	27	24
Severe dependence (score 5-8)	12	15	23
Total dependence (score 0-4)	16	9	19
Confusion			
Cognitively intact	32	19	20
Mild confusion	54	50	45
Severe confusion	14	31	34
Amended index of ADL			
No dependent functions	26	10	8
Dependent in bathing	17	29	13
1-4 dependent functions	17	23	21
Dependent in transfer and feed	40	38	56
Diagnosed at admission with			
Dementia	22	47	39
Cardio-vascular disease	23	18	19
Respiratory disease	13	15	14
Malignancy	3	5	9
Stroke	18	19	21
Arthritis	41	30	32
Major reasons for admission			
Physical needs	82	75	79
Mental health needs	32	47	44
Carer needs	38	43	39
Housing problem	27	6	15
Lack of motivation	26	28	21
Social contact	7	2	2
Other	6	13	5

Table 4.4: Changes in dependency for people who were discharged to a private household, by dependency on admission

Barthel score on admission	Improved	Same	Deterior-ated	No follow up score
Very low dependence (17-20)	-	9	2	9
Low dependence (13-17)	2	8	1	8
Moderate dependence (9-12)	4	5	2	3
Severe dependence (5-8)	5	1	1	3
Total dependence (0-4)	5	2	-	4
Total	16	26	7	28

Note: Improved = by 4 or more points
                   Same = stayed within four points
                   Deteriorated = by 4 or more points

Table 4.5: Average service receipt, by household composition, for people discharged to private households who continued to receive community services

Service details	Living alone n=22	Living with others n=12
Home care hours per week	10.4	11.4
Community nurse visits per week	1.7	1.2
Meals delivered per week	0.7	1.1
Day care days per week	0.9	0.8
Respite days per year	13.9	28.5

Chapter 5
Length of Stay and Mortality

5.1 Introduction

This chapter determines the expected length of stay and survival for someone aged 65+ admitted for the first time to a residential or nursing home as a supported resident[5]. It is based on the first 30 months of the survey of admissions. It provides necessary background statistics for the following two chapters on changes in health and the costs of care. An example is given of how to calculate expected survival given circumstances at admission.

5.2 Methodology

5.2.1 The Survey

Previous chapters have described the sample and the method of establishing information about residents at each stage of the study. Information on deaths was sought at each stage from the person providing the information. In addition a number of deaths were reported during the preparatory stages of the 6, 18 and 30 month follow-ups.

Immediately after the 30 month follow-up, the position was as follows:

Known to be alive	752[6]	29%
Known to be dead	1572	61%
Uncertain	252	10%
Total	2576	

The uncertain group included those where the Care Home was not responding to our enquiries, those who were reported as having moved at various stages and had not been successfully recontacted, and those who had elected not to provide further information at the 6 or 18 month stage.

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[5] These are people who were assessed by social services departments in the PSSRU admissions survey and who were subsequently admitted to residential or nursing home care on a long-stay basis, on the assumption that part or all of their costs would be met by the social services department.

[6] One less than reported in DP1537, chapter 4, due to discovery of a duplicate case.

As this analysis is leading towards the total life-time cost following first admission as a supported resident, some individuals have been excluded from the remaining analysis in this chapter who appear not to be first-time admissions to supported care. This includes people identified in the admissions survey who were in fact transferring between residential and nursing homes, or moving between homes for other personal reasons. However we have retained those people transferring from a short-term place, those previously admitted on an emergency basis and those previously self-funding. This leaves 2384 people who are assumed to be first-time long-stay admissions to supported care, including all people who were living at home at the time of admission or who were admitted direct from hospital.

5.3 Survival

5.3.1 Evidence

The most important factor in determining the length of time for which care will be required following admission to a care home is the individual's subsequent mortality. A detailed analysis was contained in our previous report (Bebbington et al, 1999, chapter 4) and will be presented in more summary form here. However, some data corrections have been incorporated into the database, in particular where we have found some people alive at 18 months that were previously though to be lost to the study after one month, so that estimated life expectancies are very slightly greater than those presented previously (though not to an extent that would much affect our earlier conclusions).

As is reported above, survival up to 30 months is uncertain for 252 people in the original sample. However, we do have some information about nearly all of these. All but one were tracked for some time beyond the initial point of admission, and we are able to say that each person was known to be alive up to a certain point. This information is of use to the survival models employed in this analysis. In addition, of those known to have died, date of death is unknown for 51 (3%). For the purpose of the analysis that follows, a date of death has been imputed for each of these, chosen between the date at which they were last reported alive and the date on which their death was reported. Most of these cases are where someone was admitted to hospital, and judging from similar cases, it is likely that death would have been fairly soon after admission to hospital. In other cases the date is chosen at random[7].

5.3.2 Survival Analysis

The remainder of this analysis is based on standard life table methods, now commonly known as survival analysis, as described in the previous report (Bebbington et al, 1999, chapter 4).

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[7] Information about death will completed at the 42 month sweep using the ONS Register of Deaths.

The virtue of this approach is that it takes account of information about people for as long as that information is available. The methods commonly centre on the calculation of *hazard rates* which predict the probability of dying in a given time interval after admission, given survival up to that point.

Table 5.1 shows the life table on a month by month basis for the first 30 months. This gives, for the combined sample, the cumulative probability of survival and the hazard (life table mortality) rates. The median is 19.0 months. The hazard rates are a bit variable, and there seems to have been under-reporting in the final month of each period (18 and 30 months). The general trend appears to be a rapid fall in the mortality rate during the first six months to a low of around 2.5 per cent per month, with some indication of a gradual rise thereafter to around 3.5 per cent per month.

The median survival for people admitted to nursing beds is 11.0 months and for residential beds is 25.7 months. The initial death rate is much higher for people admitted to nursing beds, who suffer particularly high mortality in the first three months following entry. The probability of dying in the first three months is 35 per cent compared with 13 per cent for people admitted to residential care. In the longer term the hazard rates get closer but are always higher for people in nursing beds.[8]

5.3.3 Factors affecting survival

The hazard rate can be used to provide a means of determining what effect certain factors at admission have on survival. In order to do this we have to assume *proportionality of hazards,* which implies that although the hazard rates for the categories of key explanatory variables, such as people in residential and nursing homes, may differ through time, throughout they remain roughly in constant ratio to one another. This assumption was examined in detail in the previous report and found to be reasonable.

Table 5.2 shows the results of fitting this model using a range of risk factors that should be known at the time of admission[9]. This analysis is based on 2189 individuals. The 196 who have been excluded are those who were never traced beyond the original survey, and those with missing information for any of the items in this table.

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[8] Further details are given in the previous report, which also considers the robustness of these estimates to the assumptions about date of death where this is not known at 30 months.

[9] This table is includes a slightly different range of factors from those in the previous report, in response to comments made about that report. Details of the Barthel scale and the MDS Cognitive Impairment scale are available in chapter 6.

The final column of table 5.2 shows the relative risk of each factor. This column may be interpreted as follows:

- Women have a risk rate which is only 74% of men: in any short period they are only ¾ as likely to die (all else being equal, such as age, health at the outset etc).
- People admitted with a malignancy have a relative risk rate thereafter which is 2.44: in any short time period they are more than twice as likely to die as those who did not have a malignancy at admission.

And so on. To summarise table 5.2:

- The factors at admission that significantly raise subsequent mortality are, in order of their statistical significance: having a malignancy (cancer), having a low Barthel score (high disability), old age, being a man, being admitted from a hospital, having a respiratory illness. Cognitive impairment is not quite statistically significant in table 5.2, though it might have been if we had chosen to scale it slightly differently, so on this evidence it is possible that it increases mortality.
- The factors at admission that significantly reduce subsequent mortality are: being younger, being a woman, being admitted to a residential home, having a high Barthel score, being admitted from another care home (many of whom are spend-down cases).
- Factors that make no difference (after other factors are allowed for) include region of residence, being diagnosed with dementia, depression, cardio-vascular disease, or admitted following a stroke, being incontinent.

The model of table 5.2 can be used to predict the probability of survival up to 30 months of people with particular characteristics on entry. An illustration is given in table 5.3. For a woman aged 75-84, admitted from a hospital, with a Barthel score below 5, mild cognitive impairment, but no diagnosed illnesses in the above list, the median survival is likely to be 12 months. This is without knowing whether she entered a residential or nursing home, which would have a considerable further influence on expected survival.

The characteristics listed in table 5.2 mainly reflect the circumstances of the individual immediately prior to the time of first admission. The list does include local authority of origin, which is not a significant factor to outcome. It would also be of considerable interest to use this approach to examine how the home itself, particularly the facilities, staffing levels and regime, influence outcome. This may be possible with some additional research.

The close relationship between dependency and survival among elderly people in institutions echoes the findings of Donaldson et al (1980) in the last large-scale longitudinal study of this type in the UK, though that study was not based on admissions and so was unable to estimate life expectancy within institutional care.

5.3.4 Average length of survival

The above analysis gives an indication of the factors at admission that will affect typical length of life, and so length of stay in care homes. However, when planning in aggregate for the cost consequences of admissions, what is important to determine is not the median, but rather the expected, or average survival given these factors. The average and median length of stay can be considerably different, due to a small proportion of people who may remain many years in a care home, and so who add to overall average life expectancy. In principle we will not know the actual average until the last person from this cohort has died, which might be as long as 25 years or more. However, as the number of people surviving becomes small, it is possible to make assumptions about will happen in future to the remainder, which enables an average to be calculated.

This can be done using a forecasting model. Such a model must make assumptions about the processes affecting future mortality, and the model of table 5.2 cannot be used for this purpose, because it is non-parametric. Table 5.1 showed that the hazard rate drops quickly during the first 6 months, and stays fairly level thereafter, though with a possible slight rising trend after 30 months. We shall, therefore, consider the implications of assuming that after 30 months, the hazard rate will remain at a constant rate for each survivor, corresponding to the average level between 12 and 30 months, but making allowance for the factors at admission which we have already shown influence survival.

This model is similar in concept to that described in the previous section except that it carries the additional assumption that life expectancy from 30 months onwards follows a Poisson process. Estimation by standard maximum likelihood methods generates the coefficients shown in table 5.4. This model predicts an average death rate of 3.9 per cent per month among survivors at 30 months, and, on average, another 30 months of life for these survivors. Combined with the data on people already died, the average length of survival is predicted to be 28½ months following admission while just one person in 20 will survive for 8 years or more.

This model has been used to microsimulate survival of the 916 people not known to have died by the end of the study. Microsimulation is used for the later cost predictions that will be made. Of course it is not possible to say how accurate this model will prove to be. Table

5.1 does suggest that monthly death rates are fairly stable, though possibly rising slightly towards 30 months, which would imply lower survival. If the death rate were to be one third higher than predicted by the above model (average 5.1 per cent per month), average life expectancy would be 25½ months, whereas if it were to fall by a similar proportion (average 2.9 per cent per month), average life expectancy would be 32 months. These are probably the extremes of prediction.

5.4 Conclusion

Information about the expected length of stay for people admitted to residential and nursing home care is an important building block for predicting lifetime costs as well as for planning purposes. Primarily length of stay will be determined by mortality. The analysis of data up to 30 months after admission shows:

- The median survival for the whole sample is 19.0 months (± 0.8 months). For those originally admitted to nursing homes it is 11.0 months (± 0.9 months), and for residential care is 25.7 months (± 0.9 months).
- Mortality rates are high initially, especially in nursing homes, but after about twelve months settle to around 3% per month (for the combined sample), though possibly rising slowly by 30 months.
- The factors at admission that significantly raise subsequent mortality are, in order of their significance: having a malignancy (cancer), having a low Barthel score (high disability), old age, being a man, being admitted to a nursing home, being admitted from a hospital, having a respiratory illness.
- There are no significant differences between local authorities in survival outcomes, after taking into account factors such as dependency on admission.
- As a few residents will live for a long while, the average length of survival is much greater than the median. Given the evidence to 30 months, our best estimate is 28½ months and almost certainly in the range 25½ - 32 months. This is much less than recent speculation, but the model tentatively forecasts about 5 per cent of people will survive 8 years or longer after admission.

After the 42 month wave is complete it will be possible to estimate survival a great deal more accurately and this will improve the estimation of lifetime costs.

Table 5.1: Life tables for first time admissions to publicly funded residential and nursing homes during the first 30 months

Month	Number at start of month	Number lost to study during month	Number exposed to risk	Deaths during month[1]	Proportion surviving month	Cumulative proportion survivors	Hazard rate
1	2385	1	2384½	215	0.9098	0.9098	0.0944
2	2169	25	2156½	157	0.9272	0.8436	0.0756
3	1987	0	1987	112	0.9436	0.7960	0.0580
4	1875	0	1875	71	0.9621	0.7659	0.0386
5	1804	0	1804	72	0.9601	0.7353	0.0407
6	1732	0	1732	52	0.9700	0.7133	0.0305
7	1680	67	1646½	55	0.9666	0.6894	0.0340
8	1558	0	1558	35	0.9775	0.6739	0.0227
9	1523	0	1523	35	0.9770	0.6585	0.0232
10	1488	0	1488	39	0.9738	0.6412	0.0266
11	1449	0	1449	33	0.9772	0.6266	0.0230
12	1416	0	1416	31	0.9781	0.6129	0.0221
13	1385	0	1385	50	0.9639	0.5908	0.0368
14	1335	0	1335	47	0.9648	0.5700	0.0358
15	1288	0	1288	44	0.9658	0.5505	0.0348
16	1244	0	1244	34	0.9727	0.5354	0.0277
17	1210	0	1210	31	0.9744	0.5217	0.0260
18	1179	0	1179	17	0.9856	0.5142	0.0145
19	1162	129	1097½	29	0.9736	0.5006	0.0268
20	1004	0	1004	30	0.9701	0.4857	0.0303
21	974	0	974	19	0.9805	0.4762	0.0197
22	955	0	955	28	0.9707	0.4622	0.0298
23	927	0	927	22	0.9763	0.4512	0.0240
24	905	0	905	25	0.9724	0.4388	0.0280
25	880	0	880	25	0.9716	0.4263	0.0288
26	855	0	855	30	0.9649	0.4114	0.0357
27	825	0	825	29	0.9648	0.3969	0.0358
28	796	0	796	31	0.9611	0.3814	0.0397
29	765	0	765	31	0.9595	0.3660	0.0414
30	734	0	734	16	0.9782	0.3580	0.0220

[1] *Month of death is imputed in 51 cases.*

Table 5.2: Proportional hazard model for factors affecting death rates (in first 30 months) in residential and nursing homes

	Model coefficient	Standard error	Wald test statistic	df	Sig at 1% level?	Relative risk
Area of origin			1.78	2	No	
Shire County	0.0000	-				1.00
Metropolitan District	-0.0740	0.0565				0.93
London	-0.0631	0.0974				0.94
Gender			23.77	1	Yes	
Man	0.0000	-				1.00
Woman	-0.2995	0.0614				0.74
Age at admission			47.65	2	Yes	
65-74	0.0000	-				1.00
75-84	0.2866	0.0972				1.33
85+	0.5832	0.0968				1.79
Diagnosed illness on entry						
Dementia	-0.0273	0.0685	0.15	1	No	0.97
Depression	0.0422	0.0819	0.27	1	No	1.04
Cardiovascular	0.0895	0.0892	1.68	1	No	1.09
Respiratory	0.3068	0.0750	16.71	1	Yes	1.35
Malignancy	0.8915	0.0892	99.94	1	Yes	2.44
Stroke	-0.0247	0.0686	0.00	1	No	0.98
Incontinent (urine or faeces)	-0.0757	0.0753	1.01	1	No	0.93
Barthel Score on entry			83.00	3	Yes	
0-4	0.9196	0.1013				2.50
5-8	0.4152	0.0829				1.51
9-12	0.3444	0.0759				1.41
13+	0.0000	-				1.00
MDS Cognitive Scale			4.65	2	No	
Intact	0.0000	-				1.00
Mild impairment	0.1268	0.0790				1.14
Severe impairment	0.2058	0.0957				1.23
Source of admission			14.73	3	Yes	
Private household	0.0000	-				1.00
Care Home	-0.1285	0.1310				0.88
Hospital	0.1887	0.0608				1.21
Other	0.3686	0.2152				1.45

Based on a Cox Proportional Hazard Model (see text for explanation). For Area, Gender, Age, Barthel Score, MDS Cognitive scale, Source of Admission; risks are relative to the group with a coefficient of 1.00. For Diagnosed illness and Incontinence, risks are relative to someone without this condition.

Table 5.3: Illustrative calculation of life expectancy in publicly funded residential/ nursing home care, given circumstances on admission

What is the median expected survival and the probability of surviving 12 months; for a person with the following characteristics?

	Coefficient from table 4.4
Living in shires	0.0000
Woman	-0.2995
Aged 75-84	0.2866
No diagnosed medical conditions	0.0000
Incontinent	-0.0757
Barthel score 0 – 4	0.9196
Mild cognitive impairment	0.1268
Admitted from hospital	0.1887
Total score	1.1465

Hazard ratio 'r' (compared with general average) = exp(1.1465)/exp(0.8126) = 1.3964. (Note that 0.8126 is the score at the average of all explanatory variables).

Probability of survival 'm' months can be estimated from = Π (2 - r.h_i) / (2 + r.h_i) where the product is over i = 1, …,m; and h_i denotes the monthly hazard rate as given in table 4.2. The following table shows the first 12 months of this calculation:

Month	Hazard rate h_i	Specific hazard rate r.h_i	Probability of surviving month (2-rh_i)/(2+rh_i)	Cumulative probability of survival
1	0.0944	0.1318	0.8763	0.8763
2	0.0756	0.1056	0.8997	0.7885
3	0.0580	0.0810	0.9222	0.7271
4	0.0386	0.0539	0.9475	0.6889
5	0.0407	0.0568	0.9447	0.6508
6	0.0305	0.0426	0.9583	0.6237
7	0.0340	0.0475	0.9536	0.5948
8	0.0227	0.0317	0.9688	0.5762
9	0.0232	0.0324	0.9681	0.5579
10	0.0266	0.0371	0.9635	0.5375
11	0.0230	0.0321	0.9684	0.5205
12	0.0221	0.0309	0.9696	0.5047

So in this example the probability of surviving 12 months is just over 50 per cent making one year the median length of survival.

Table 5.4: A model for forecasting survival beyond 30 months

Life expectancy in months (given survival to 30 months) = 1/exp(-z)
Where 'z' is given by the sum of the following:

Constant	3.643
Age at admission	
65-74	0.000
75-84	-0.161
85+	-0.619
Gender	
Male	0.000
Female	0.177
First placement	
Nursing home	0.000
LA Residential home	0.472
Voluntary residential home	0.396
Private residential home (including dual registered)	0.252
Admitted with	
Respiratory/chest disease	-0.337
Malignancy	-0.369
Barthel score on admission	
0-4	-0.872
5-8	-0.132
9-12	-0.310
13+	0.000

Chapter 6
Health Outcomes of people admitted to Care Homes

6.1 Introduction

A major aim of the longitudinal survey has been to establish the outcome of an admission to a care home, in terms of the health and survival for the person who is admitted. There are two applications for this investigation.

- *As a guide to quality.* A concern of care homes is to provide an enabling environment and to support and maintain the health of residents as far as is practicable, and these are criteria by which homes may be judged. Arguably, one home is better than another if residents in similar circumstances on admission live longer, enjoy better health, and are more able to manage basic activities.
- *For planning.* A goal of the work is to investigate the practicality of predicting subsequent health following admission, as a guide to care planning.

This chapter examines changes in the health of survivors in two ways:
- Dependency, measured by the Barthel ADL scale;
- Cognitive state, as measured using the MDS.

There are certain reliability issues with change measures in longitudinal surveys. Appendix 6A summarises these.

6.2 Changes in dependency

The Barthel scale is a well known and standard scale of dependency covering 8 activities. A high score counts as relatively able. Scores run from 0 to 20, and these are often classified into four groups. Table 6.2 shows the distribution at the time of admission.

The key evidence on change is summarised in table 6.3. This shows the transition between disability states, measured by the grouped Barthel scale. Points to note from this table:
- Many people improve as well as get worse.
- Rates of change are greatest in the first 6 months.

Table 6.4 summarises these changes, showing the proportion of people who make significant changes between survey waves. This shows clearly that the general trend is towards greater dependency, even though a surprising number improve (by 4 or more points on the Barthel scale) in the first six months. However thereafter comparatively few improve.

This initial improvement might be due to particular difficulties around the time of admission, which resolve themselves later[10]. It is of interest to ask in what respects are improvements achieved, and conversely, what aspects of dependency are least likely to be improved. This is examined in table 6.5. This table shows that improvements can occur in aspect of dependency, particularly in the first 6 months; while declines are similar, but the rate of decline continues through time. The rate of improvement of disabled people is greater than the rate of decline for able people initially for many aspects of dependency. However, as there are fewer disabled than able people (except for dressing and bathing), overall there is a decline.

- *Feeding* stands out as the area where most improvements are made following admission. Improvements continue to occur later on as well, to a greater extent than any other ability;
- *Continence* likewise shows good gains immediately following admission, and is notably the ability least likely to decline. However if gains are not made immediately after admission, they are less likely to occur later. This finding probably reflects improved management of incontinence following admission, rather than any great improvement in the underlying condition.
- *Mobility* also stands out as an ability that is well maintained. Again, this is probably due to the regime in homes providing support to prevent residents becomes wholly bed or chair bound.

The group of people who improve shortly after admission, particularly those who as a result of their improvement have a moderate or low level of dependency, might seem good candidates for measures to postpone an early long-term admission. We have compared these with the remainder to see if they could have been identified at the time of admission. The criterion for an improvement is a gain of 4 or more points on the Barthel scale, with a final score exceeding 8. Because individuals with initially high scores may be unable to improve that much, the analysis is confined to those who scored 14 or less on admission.

Table 6.6 shows factors that are significantly different between these 'improvers' and others. It turns out to be the people who are comparatively independent at time of admission that

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[10] It should be noted that at the time of admission, the questionnaire was completed by social workers, while at later stages, by staff of care homes. This may or may not make a difference.

improve most. What is particularly noticeable is that it is people with specific health diagnoses on admission that are the most likely to improve. However, surprisingly, these are not people discharged from hospital. More of the people admitted from private households improve.

So it is not premature discharge from hospital that provides the greatest missed opportunities for possible rehabilitation. Rather it is among people admitted from private households with chronic diseases. Possibly these are diseases that may undergo remission, and thus enable the person to be more independent, at least for a while.

It would be possible to use the factors that are significant in table 6.6 to generate an equation that predicts, from the circumstances at admission, who is likely to make significant improvements in their dependency by 6 months. However, the level of prediction turns out to be too small for this to have much practical use. The level of prediction gets even lower at 18 and 30 months.

6.3 Changes in Cognitive Function

Cognitive functioning was measured in this study using the MDS Cognitive Functioning Scale. We have described this scale in full in previous reports (Bebbingon et al, 1999) It is based on 5 items, but combined in a complex manner as shown in table 6.7. It produces seven levels of functioning, but for this analysis we have reduced this to three, by combining levels 0; 1, 2 and 3; 4, 5 and 6.

It should be noted that the questionnaire did not ask whether the resident was 'comatose'. It is assumed that anyone who is in such a state would also be reported as unable to make decisions and dependent with regard to feeding, so would automatically be classified at the highest level anyway. Given that the analysis was based on three broad categories, it is inconceivable that anyone who might be described as comatose would fall into either of the lower two groups.

Table 6.8 shows the situation at the time of admission. The majority were described as showing some degree of problem. The transition rates of table 6.9 show that there were as many recoveries as declines in the first 6 months, when indeed the majority of survivors were in the 'mildly confused' category.

However at the next two waves more people decline than improve, so that of the survivors, 34% were severely impaired at the outset compared with 48% at the end of the study.

No factors on admission appear to be predictive of subsequent changes in cognitive functioning.

6.4 Healthy Life Expectancy Following Admission

A Markov chain model has been used to estimate healthy life expectancy following admission, based on the transition rates shown in tables 6.3 (Barthel scale) and 6.9 (MDS Cognitive Functioning Scale). This model, which is regarded as the best method of estimating healthy life expectancy but has rarely been applied in practice, has been used to estimate the proportion of remaining life that will be lived at various health states, given health state on admission. Like the survival model in chapter 5, it assumes proportionality: that is although the expected length of remaining life may vary depending on age, gender etc, the proportion at different health states will be similar. Details of the model are given in appendix 6B.

Table 6.10 shows the outcomes. From part A, a person who has low dependency on admission can expect to live about half their remaining life at this low level of dependency, while a person at total dependency can expect to live about two-thirds of their remaining life at this level.

Although median survival and subsequent expectation of healthy life are very different depending on life expectancy at the outset, it is worth noting that for a typical person, the expectation of life in total dependency in a care home is about 4 months regardless of their state of health on admission.

For cognitive functioning, table 6.10 part B it also appears that those who are admitted with severe problems are likely to spend the greater part of their remaining life in that state. Those who are intact on admission can however expect to spend more than half their life with some degree of problem.

6.5 People with Low Needs in Care Homes

It has been suggested that significant numbers of people are admitted to care homes though their needs do not seem to warrant it. For this reason we looked at people who had a low Barthel score and no cognitive impairment at the time of admission. 14 per cent of admissions are in this group. This rate declines only slightly from one wave to the next. However, of the people who survived through the 30 months, just three per cent were in this category at all stages. This represents just one per cent of all admissions. The implication is that there are not large numbers of relatively healthy people supported by local authorities in residential care, though health may fluctuate once in care.

6.6 Conclusion

This chapter has been concerned to provide descriptive information which may help both individuals and organisations with the planning of care for people admitted to a care home. With regard to both dependency and cognitive function, the evidence suggests that survivors at 6 months may on average, be a little better off than at the time of admission, but thereafter there will be a slow but steady decline. The improvement by 6 months is most marked in those activities of daily living that might relate to being in a better controlled environment, rather than any real indication that people have recovered in a way that might make them more fit to return to private households. Though some people seem quite independent and mentally alert at each stage of the survey, only one per cent of all those admitted were in this condition at every wave of the survey. The implication is that there is not an obvious group for whom such a placement is clearly inappropriate.

Table 6.1: Barthel Index of Activities of Daily Living

The Barthel Index is computed as the sum of the scores for the ten items shown, and ranges from 0 (highest level of dependency) to 20 (lowest level of dependency).

Function	Score	Description
Bowels	0 1 2	Incontinent (or needs to be given enemata) Occasional accident (once/week) Continent
Bladder	0 1 2	Incontinent, or catheterized & unable to manage Occasional accident (max once per 24 hours) Continent (for over 7 days)
Grooming	0 1	Needs help with personal care Independent face/hair/teeth/shaving (implements provided)
Toilet use	0 1 2	Dependent Needs some help, but can do something alone Independent (on & off, dressing, wiping)
Feeding	0 1 2	Unable Needs help cutting, spreading butter etc Independent (food provided in reach)
Transfer	0 1 2 3	Unable – no sitting balance Major help (1 or 2 people, physical), can sit Minor help (verbal or physical) Independent
Mobility	0 1 2 3	Immobile Wheel chair independent including corners etc Walks with help of 1 person (verbal or physical) Independent (but may use any aid, eg stick)
Dressing	0 1 2	Dependent Needs help, but can do about ½ unaided Independent (including buttons, zips, laces, etc)
Stairs	0 1 2	Unable Needs help (verbal, physical, carrying aid) Independent up & down
Bathing	0 1	Dependent Independent (or in shower)

Table 6.2: Dependency at the time of admission, among people admitted to residential and nursing home care

Barthel dependency score	%
Total (0-4)	18
Severe (5-8)	23
Moderate (9-12)	24
Low (13-16)	21
Very low (17+)	13
Base	2349

Table 6.3: Transition rates for levels of disability (Barthel)

At 6 months	At admission			
	Total %	Severe %	Moderate %	Low %
Dead	55	35	34	23
Total	27	15	8	3
Severe	11	25	17	5
Moderate	5	13	16	17
Low	2	11	25	52
(Base)	(363)	(461)	(482)	(631)
Missing %	14	16	14	22
(Total)	(421)	(549)	(570)	(809)

At 18 months	At 6 months			
	Total %	Severe %	Moderate %	Low %
Dead	54	35	28	21
Total	36	22	9	2
Severe	9	32	25	7
Moderate	2	7	24	15
Low	0	4	14	56
(Base)	(186)	(221)	(214)	(410)
(Missing %)	17	19	18	19
(Total)	(223)	(273)	(262)	(507)

At 30 months	At 18 months			
	Total %	Severe %	Moderate %	Low %
Dead	42	36	30	19
Total	49	25	14	4
Severe	8	29	22	6
Moderate	1	7	26	16
Low	0	3	8	55
(Base)	(137)	(159)	(141)	(265)
Missing %	18	15	11	17
(Total)	(166)	(187)	(159)	(318)

Interpretation: At 6 months, 55 per cent of those whose dependency is 'Total' on admission were dead (based on 363 people). Of those who scored Total on admission, 14 per cent were missing at 6 months (based on 421 people).

Table 6.4 Changes in dependency (summary)

	During first 6 months	*Between 6 and 18 months*	*Between 18 and 30 months*
Improved	12%	3%	3%
Same	34%	39%	43%
Declined	13%	13%	15%
Died	40%	45%	39%
Base: (Change)	(1937)	(1031)	(702)

Improvement = Gain of at least 4 points on Barthel scale
Declined = Loss of at least 4 points on Barthel scale

Table 6.5: Improvement and Decline in Dependency Activities between survey waves

A. Proportion of disabled people who became able (improvement)

	Between admission and 6 months		Between 6 and 18 months		Between 18 and 30 months	
	%	*N*	*%*	*N*	*%*	*N*
Continence	41	(370)	21	(187)	16	(171)
Grooming	36	(655)	26	(328)	12	(252)
Using Toilet	35	(637)	18	(314)	11	(253)
Feeding	52	(550)	24	(210)	24	(187)
Transfer	31	(677)	16	(327)	10	(241)
Mobility	31	(413)	18	(250)	11	(182)
Dressing	23	(976)	11	(525)	5	(363)
Climbing Stairs	26	(677)	17	(452)	16	(335)
Bathing	6	(1277)	4	(765)	3	(534)

B. Proportion of able people who became unable (decline)

	Between admission and 6 months		Between 6 and 18 months		Between 18 and 30 months	
	%	*N*	*%*	*N*	*%*	*N*
Continence	17	(1043)	18	(636)	23	(403)
Grooming	30	(772)	29	(506)	30	(329)
Using Toilet	27	(789)	25	(520)	28	(330)
Feeding	21	(878)	24	(617)	26	(386)
Transfer	24	(735)	22	(507)	26	(339)
Mobility	20	(917)	18	(583)	19	(395)
Dressing	47	(452)	31	(308)	36	(219)
Climbing Stairs	45	(740)	31	(376)	39	(244)
Bathing	78	(156)	63	(73)	59	(51)

Definitions of ability used in above table

	Able	*Unable*
Continence (bowels, bladder)	Levels 1 or 2 (for both)	Level 0 (for either)
Grooming, bathing	Level 1	Level 0
Using toilet, dressing, climbing stairs	Levels 1 or 2	Level 0
Transfer, mobility	Levels 2 or 3	Levels 0 or 1
Feeding	Level 2	Levels 0 or 1

Levels are as defined in table 6.1.

Table 6.6 Factors associated with Barthel Score improvement in the first 6 months

	Prop^n of Improvers %	Sig different? (1%)
Area of origin		No
Shire County	23	
Met District	21	
London	27	
Gender		No
Man	24	
Woman	23	
Age at admission		No
65-74	23	
75-84	21	
85+	25	
Diagnosed illness on admission		
Dementia	23	No
Depression	32	Yes
Cardiovascular	34	Yes
Respiratory	32	Yes
Malignancy	33	No
Stroke	20	No
Incontinent (urine or faeces)	20	No
Bathel score on entry		Yes
Total	15	
Severe	25	
Moderate	28	
Low*	18	
Confusion		No
Intact	24	
Mild Impairment	24	
Severe Impairment	24	
Source of admission		Yes
Private household	28	
Care home	17	
Hospital	22	

Analysis based on 929 individuals with an initial Barthel score of 14 or below.
* Score 13-14 only.

Table 6.7: MDS Cognitive Performance Scale

MDS CPS item	Level	Description
Comatose	0 1	No Yes
Short-term memory	0 1	Memory OK Memory problem
Decision making	0 1 2 3	Independent Modified independent Moderately independent Severely impaired
Understood	0 1 2 3	Understood Usually understood Sometimes understood Rarely/never understood
Eating	0 1 2 3 4	Independent Supervision Limited assistance Extensive assistance Total dependence

Computation of Impairment and Severe Impairment Counts for Constructing Scale

Impairment/Severe Impairment Counts	Components	Levels
Impairment count (IC)	Decision making Understood Short-term memory	1,2 1,2,3 1
Severe impairment count (SIC)	Decision making Understood	2 2,3

Decision Rules for Scoring MDS Scale

Score	MDS CPS Category	Decision Rule
6	Very Severe Impairment	Comatose = 1, or Comatose = 0 & Decision making = 3 & Eating = 4
5	Severe Impairment	Comatose = 0 & Decision making = 3 & Eating ≠ 4
4	Moderately Severe Impairment	Comatose = 0 & Decision making ≠ 3 & IC ≥ 2 & SIC = 2
3	Moderate Impairment	Comatose = 0 & Decision making ≠ 3 & IC ≥ 2 & SIC = 1
2	Mild Impairment	Comatose = 0 & Decision making ≠ 3 & IC ≥ 2 & SIC = 0
1	Borderline Intact	Comatose = 0 & Decision making ≠ 3 & IC = 1
0	Intact	Comatose = 0 & Decision making ≠ 3 & IC = 0

Note that the Longitudinal Survey excluded the item describing 'Comatose State'.

Table 6.8: Cognitive functioning at the time of admission, among people admitted to residential and nursing home care

MDS Cognitive Functioning level	%
Severe confusion (levels 4,5,6)	34
Mild confusion (levels 1,2,3)	46
Intact (level 0)	20
Base	2192

Table 6.9: Transition rates for levels of Cognitive Functioning

At 6 months	At admission		
	Severe %	Mild %	Intact %
Dead	41	38	40
Severe	34	15	4
Mild	22	34	24
Intact	3	13	31
(Base)	(655)	(861)	(384)
Missing %	12	14	14
(Total)	(744)	(1002)	(446)

At 18 months	At 6 months		
	Severe %	Mild %	Intact %
Dead	48	30	33
Severe	39	22	5
Mild	12	41	25
Intact	1	7	38
(Base)	(351)	(491)	(230)
Missing %	14	14	12
(Total)	(410)	(570)	(261)

At 30 months	At 18 months		
	Severe %	Mild %	Intact %
Dead	36	29	17
Severe	54	26	7
Mild	10	38	28
Intact	0	8	47
(Base)	(286)	(314)	(138)
Missing %	10	17	11
(Total)	(318)	(378)	(155)

Interpretation: At 6 months, 41 per cent of those whose functioning is 'Severe' on admission were dead (based on 655 people). Of those who scored Severe on admission, 12 per cent were missing at 6 months (based on 744 people).

Table 6.10: Life Expectancy at Various States of Health

A.   Dependency (Grouped Barthel Scale)

	Dependency on Admission			
	Total	*Severe*	*Moderate*	*Low*
Median life expectancy (months)	6.6	15.9	18.8	27.5
Proportion of remaining life at				
Total dependency	64%	30%	22%	16%
Severe dependency	20%	39%	21%	14%
Moderate dependency	9%	14%	28%	18%
Low dependency	7%	17%	29%	51%
Base	(427)	(556)	(576)	(820)

B.   Cognitive Functioning (Grouped MDS Scale)

	State on Admission		
	Severe	*Mild*	*Intact*
Median life expectancy (months)	14.9	20.2	23.0
Proportion of remaining life at	62%	35%	26%
Severe	30%	49%	34%
Mild	8%	16%	40%
Intact			
Base	(758)	(1107)	(446)

Interpretation: A person who is totally dependent on admission can expect to live for 6 months.   Their expectation is that 64% of this will be in total dependency, 20% in severe dependency etc.

Appendix 6A: Reliability of Measures

6A.1 Change variables

Change in longitudinal surveys is normally measured by the simple difference between measured health at two points in time. We have followed that convention, though there are some known problems whenever health cannot be measured with perfect reliability. One example is the *End Effect*. People who have a perfect score can only get worse. Some will seem to do so merely because of imperfect reliability. So in general it will appear that well people get worse, ill people get better, even if in reality there is no change. This effect actually will occur throughout the range of the health measure, to produce *Regression Towards the Mean.* It has been proposed that changes are better measured by regression adjusted estimates of final health than by difference, in order to allow for this. However, results are less easily interpreted, and we have stuck to the conventional method in this chapter.

A general caveat about analysing changes in health concerns how health state was determined. If it simply reflects the state on the day of the survey, then health changes will be subject to considerable volitility, with the problems mentioned in the previous paragraph. Elderly people in care homes do tend to experience fluctuations in their health. The measures we have used refer to the 'general' rather than the immediate state of health. However this is less precise, and it is likely that the resulting reports will tend to overestimate average levels of health at a point in time. Both the Barthel and MDS are well established scales that have been well-tested for their reliability, but these problems are not eliminated. The result is that there is inevitably a certain amount of 'noise' in measuring change which may reduce our ability to predict or explain why changes occur.

6A.2 Missing data

Missing data is a major problem for all longitudinal surveys. It is particularly a problem for health surveys, since there is a likelihood that the ability and willingness to respond will be related in some way to changes in health. The present survey has enjoyed exceptionally low levels of missing data, and where data is missing this can nearly all be attributed to the head of home rather than problems contacting the resident, which means that missing data is perhaps less likely to be associated with the person's circumstances than is the normal case. Nevertheless it is sensible to take note of missing data. Tables 6.3 and 6.10 report the health of people who were missing at the next stage. It appears that people with low initial dependency were more likely to be missing later, but this is not true subsequently. This might imply that the remaining sample are biased towards being more dependent on average, but if so the bias would be a small one. There are no obvious biases with regard to cognitive

functioning. On this evidence we have chosen not to make any adjustment for possible bias due to differential missing data.

Appendix 6B: Healthy Life Estimates

The estimates in table 6.10 are constructed as follows.

Construct:
$$T_x = \{\underset{\sim}{1} \; R_x\} \quad x = 1,2,3$$

Where Rx denotes the 4 x 5 transition matrix shown in table 6.3 for dependency groups or the 3 x 4 matrix in table 6.10 for cognitive functioning. x=1,2,3, corresponds to the matrices for 0→6, 6→18 and 18→30 months respectively. 1 denotes the first column of the identity matrix.

Calculate
$$P_x = T_x \times P_{x-1} \quad where \quad P_0 = I$$

Then, using the standard theorem for forward Markov processes, the total expected months spent in each state is then estimated by

$$M = \sum_x \frac{n_x}{2}(P_{x-1} + P_x) \quad , \quad x = 1,2,3,...$$

where n_x denotes the number of months corresponding to x (6,12,12,…), and we take $P_x = P_3$ for x > 3. The elements of M corresponding to states other than death converge on summation. This is a 'passage time' problem with a well-known analytic solution in the case of all equal P. (e.g. M.G.Bartlett ,1962, *An introduction to stochastic processes*, chapter 3, Cambridge University Press).

This model generates an estimate of the average life expectancy for people in a given health state at the outset. However as it makes simpler assumptions about changes in state from the model of chapter 5, it gives somewhat different and rather less reliable estimates. These estimates are about 2 months less than given in chapter 5. For this reason table 6.11 describes the proportion of remaining life at given states of dependency rather than the total. This is given by:

Proportion of remaining life in state 'j' for someone in initial state 'i': $= \; m_{i,j} \Big/ \sum_j m_{i,j}$

where $m_{i,j}$ denotes the elements of M and the summation excludes j = 1 (death).

Chapter 7
Life-Time Costs within a Care Home

7.1 Introduction

This chapter determines the life-time costs to social services departments (only) for the care of someone aged 65+ admitted for the first time to a residential or nursing home as a supported resident. It is based on the first 30 months for people admitted for the first time as a supported resident (see chapter 5). It includes an analysis concerning type of care, moves between care settings and unit costs, and uses the evidence about survival that was developed in chapter 5. It develops methods for predicting expected cost from the circumstances at the time of admission, according to whether or not a placement decision has yet been made. An example is given of how to calculate expected gross life-time costs, using the prediction formula.

7.2 Methodology

Costs in this study refer to the cost to social services departments (SSDs) of the care they have agreed to provide, from the time of first admission up until the client's death. This may include community based care where a person subsequently leaves a care home; but it excludes primary health care and hospital costs, costs to housing and social security. One implication is that nursing costs will largely be included for those in nursing homes (since it is a cost to social services), but in residential homes, it will largely be excluded (since it is a cost to health authorities). Both gross and net costs are of interest, the latter being the cost after the client's contribution.

Costs are calculated on the basis of the length of time that a person spent in each type of setting, and the weekly unit cost of the care they received. The reason for this approach was that this study did not determine the actual total costs that local authorities paid during each resident's lifetime. The main source of information about costs is based on the charges that were set shortly after the client had been admitted to the home, and reported to us by the assessment officer. Thereafter the survey was conducted as far as possible in care homes without further reference to social services departments, and it was not practicable to obtain cost information from the SSD.

This approach has certain obvious methodological implications relating to the nature and quality of the information about unit costs that was supplied; and to the consequences of not knowing about any change in costs. Section 7.3 deals with these issues concerning unit costs in detail: and also with the imputation of unit costs where data is incomplete. However, the largest influence on the reliability of our results is the assumption about the likely survival of people still alive (or not known to have died) at the end of 30 months.

7.3 Gross Unit Cost Estimates

As the study did not determine the total costs that local authorities paid during each resident's lifetime, the total costs are determined by estimating the average weekly cost of the care each person received. The main source of information about charges was based on information received shortly after the client had been admitted to the home, usually from information obtained during the financial assessment. In this section and the next we will examine the implications of this with regards to:

- Changes in charges arising within homes;
- Changes in charges or costs resulting from moves;
- The need to impute charges in missing cases, particularly when people move;
- Comparability of LA homes costs with other institutions' charges;
- Net costs.

In general, where a person remained in the same type of care throughout, the gross average weekly cost has been estimated from the fee set at the outset.

7.3.1 Changes in charges within homes

We do not have direct evidence regarding changes in charges from this study. However, the PSSRU 1996 survey of care homes that was undertaken in parallel with the present survey did investigate the pricing process in detail (Netten et al, 1999, chapter 4). The following analysis is based on reports from the heads of 459 private and voluntary homes in that study.

While charging reviews for publicly funded residents are usually carried out annually, in only one home in six did the head of home say that these reviews are conducted on an individual resident basis (table 7.1a). In the great majority of cases the reviews are undertaken collectively for all residents, though in a few cases as well as a collective review, some residents may in addition be reviewed individually. In fact, in most cases not only are the individual circumstances of residents not normally examined during review, but the homes

themselves are not directly consulted (table 7.1b). For only 20 per cent of homes was the home or its managers involved in the review.

So the processes of review themselves would appear to militate against price changes on an individual basis, say in response to a gradual change in health. Moreover, it appears unlikely that reviews of the contracted price take place on a per home basis, unless the home has changed function. Indeed, the initial contracted price appears to vary only a little with staffing levels, physical fabric, organisational arrangements, and size (Netten et al, 1999, §4.3.1).

The main factor which affects changes in the contracted weekly price for local authority funded clients through time is very probably inflationary, reflecting perhaps the local authority's desire to manage its demand-supply position for this form of care. On this basis we would consider it reasonable to assume that prices for most residents remain unchanged throughout the period they are supported in a care home, apart from inflationary changes, unless it is necessary for the resident to change homes.

7.3.2 People who move

Where people move between similar settings (e.g. from one private residential home to another, our assumption is that this is unlikely to affect costs much. It is where they move between quite different locations that the costs will change.

What matters for costing purposes is how long a person was resident in each location, and what type of services they were getting. Dates of moves are recorded but as usual there is some missing information: in 37 (21%) of cases the exact date was unknown and has been imputed between the relevant waves of the survey.

(a) *To private households*. Of the 161 people definitely known to have moved permanently, 86 returned to a private household. In 43 (50 per cent) of these cases we were able to track their subsequent use of support services, based on care manager records. This was extremely varied. Nine had no subsequent input from social services at all. At the other extreme were 8 cases receiving care worth between £200 and £300 per week[11]. In several cases this included very substantial amounts of phased residential care, up to half-time in one case, together with domiciliary support at other times. Costs of domiciliary services are estimated from the volume of care and the unit cost estimates given by Netten and Dennett (1996), and are for social services only, excluding community nursing, hospital care etc. We justify this approximate approach in terms of the fairly small number of

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[11] One reported at over £450 per week we assume is a mistake, possibly a temporary arrangement.

people concerned. The average cost is almost exactly £100 per week (outside London) and this figure has been used (with London inflation where appropriate) for all the remaining cases where the volume of support services was unknown. Of the 86 cases, 22 are known to have returned to a care home by 30 months.

(b) *To hospitals*. Sixty-seven people are believed to have moved to long-term hospital care. We discovered that a number of people who were described as having moved to long-term hospital care, died very shortly after. So the above figure excludes all who died within two weeks of the move. Even so, the period in long-term hospital care was rarely very long, only exceeding 2 months in 24 cases. Ten of the above 67 subsequently returned to a care home: almost all the remainder had died by 30 months. Hospital care has not been costed.

(c) *To other types of home*. Chapter 3 describes in some detail the degree to which people move between homes and (most importantly from a cost point of view) type of bed. As the weekly cost of the second (or subsequent home) was unknown, it has been imputed by the same method used where the initial charge was not known.

7.3.3 Imputing charges

The initial charge was not known in 314 (13 per cent) of cases. This was generally due to delays in assessments. As initial charge was more likely to be unknown in cases that died early, this group cannot be ignored, so a unit cost has been imputed in these cases. This has been done on the basis of the factors that were found to be most significant in the report by Forder and Netten (1997) based on this study. See table 7.2 for the formula used. The factors included were authority group, the type of placement, and Barthel score. Other factors found by Forder and Netten (1997) to be significant, including behaviour problems, nursing input, source of admission, and reason for admission all have a very small impact compared with the above. They also found the nature of the contract (spot, block, individual etc) to have some effect but that is excluded in this formula because often it will be unknown for those people for whom the charge is unknown.

7.3.5 Local authority homes

The great majority of people go to homes in the private and voluntary sector, and for these a charge is set which represents the total cost to social services for the care provided. This cost excludes inputs from outside the home, such as social work care managers, but after admission this input is usually quite small.

For the 176 who went to local authority homes, the cost of care is rather different. Here the social services faces direct costs for providing the labour and capital that is needed for residential care, rather than meeting a pre-set charge. This makes establishing the cost of care rather more difficult, since it becomes a combination of recurrent costs of running the home, amortised capital, and overheads in terms of administration in order to run the home (as distinct from undertaking the care management). Moreover the question of marginal costs may arise. When paying for an extra place in a privately owned institution, the local authority will have a pretty clear idea what that will be. Variations in marginal costs will be a good deal less clear when providing care in their own homes, and potentially could be very variable dependant on such factors as occupancy level. We have avoided this complication by focussing on average costs throughout. This chapter does not consider such matters as the likely impact of change in demand on costs. In essence, our focus is descriptive.

What we cannot be sure of is whether the reported costs in each case for local authority residential care is truly inclusive of all the costs that the local authority faces in providing it. However, it is pretty certain that, in general, it is not. The average unit cost reported here is £280 per week, fairly close (but a little below) the figure Netten et al (1998) report for the recurrent costs alone. Effectively capital costs are discounted, though Netten and Dennett (1996) imply that these could add a further 10 per cent to the real cost of care[12].

We have decided to analyse the data as provided, i.e. effectively to ignore capital costs, for local authority provision. This should be borne in mind through the analysis, particularly where it relates to comparisons between type of home. In general however, the comparatively small number of people in local authority homes means that this assumption is unlikely to affect other conclusions greatly.

7.4 Net Unit Cost Estimates

7.4.1 Client contribution cost
As has been reported before, remarkably few people being admitted were assessed at the point of admission as possessing significant assets of their own. The great majority are reported as having income levels that would appear to imply they are relying on state benefits. Only 10 per cent are reported as having income above £130 per week (1995/6).

A similar picture is given for assets. Although nearly one half have some capital assets, in a mere 1 per cent of cases is this reported as being above £8,000: the threshold for claiming

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[12] Greater, in subsequent editions of this annual.

Income Support at the time of the study. The value of property is reported as nil in 82 per cent of cases. Where there was property, in most cases its value was reported as unknown. Where given, property values averaged £40,000.

As a result, the client contribution was rarely likely to be greater than their personal Income Support and Residential Allowance entitlement, which varies with age, location, and type of home but at the time was unlikely to be more than £123 per week. Only 5 per cent of residents were assessed for contributions of more than this per week, while just 3 per cent were receiving top-up payments from other sources (which rarely amounted to more than £20 per week).

7.4.2 Net weekly cost

The average net weekly assessed cost to social services of the placement is £178, £100 less than the gross cost. It differs slightly according to type of home. This leads to the recommendation for imputing net weekly cost shown in table 7.2.

Based on §7.4.1, we would have expected 18 per cent of applicants to have had sufficient property capital to fund their entire costs. However this was not what was reported. In nearly all these cases the local authority was still expecting to make the main financial contribution. We must assume that the assessed client contribution reported shortly after admission does not, at this stage, include any contribution from their property. This would accord with descriptions of processes in social services, whereby the local authority normally underwrite costs until the former home is sold. Normally the proceeds will be used to offset back payments, but authorities differ in their practices on this.

7.5 Total Costs

7.5.1 Lifetime gross totals

Total costs for social services are estimated by the unit cost of the service (package), as described in section 7.3, multiplied by the length of time for which that service is used. This assumes that the unit cost of services remains constant (at 1996 prices).

To estimate the additional costs for survivors beyond 30 months, we have used the estimated survival time based on the microsimulation approach described in chapter 5, and assumed that the same service will continue to be used until death. This would appear a reasonable assumption given that as time has gone by, fewer and fewer people move from the care home in which they are currently placed.

Table 7.3 shows the gross lifetime costs to social services of a placement in a care home. These costs average approximately £27,000 for a placement in a nursing bed and £36,000 for a placement in a residential bed (at 1996 prices). Although the weekly cost of nursing care is higher, the likely length of stay is much lower.

Table 7.3 also shows that these means are very variable indeed. Many people, over one quarter of those admitted to a nursing bed, leave very quickly and cost less than £2,000. At the other extreme, around 6 per cent of all cases are projected to cost over £100,000: one or two as high as £250,000.

7.5.2 Accuracy of estimates

These estimates have of course required a large number of assumptions and approximations, described through the preceding sections, which we can summarise as follows:

- Prediction of life expectancy for individuals not known to have died within 30 months;
- Imputation of date of death where not known precisely;
- Imputation of date of move where not known precisely;
- Imputation of a gross unit cost where not given
- Imputation of gross unit cost for movers;
- Imputation of service use for some people who returned to private households;
- Assumption that costs will remain constant (at 1996 prices) while the person remains in the same care home; and
- Ignoring capital costs in local authority homes.

Of these, we believe that the first is likely to be by far the most important to the accuracy of the final estimate, because it is so difficult to make such forecasts. In chapter 5 the consequences of a rise or a fall in the monthly death rate was examined, given that that death rate had been fairly level since about a year after admission. The third part of table 7.3 shows the consequences if the monthly death rate for these survivors were to be a third higher than forecast, or a proportional amount lower. This table shows just how sensitive the estimate of the mean is to assumptions about future death rates. However, the two variants are probably extreme[13]. We suspect that the trend, if any, is towards the high death rate variant, suggesting that if anything our estimate of life-time costs will be over-estimates. However, the situation should be a great deal clearer by 42 months. If our forecasts are correct, almost exactly three-quarters of the original sample will have died by that time.

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[13] Note that estimates of the median cost is unaffected by forecasts, since more than a half have died by 30 months.

By comparison, the imputation of unit costs is not likely to have much effect. Even if the average gross weekly unit cost in these cases had been £100 higher, it would not have resulted in an increase of more than about 3 per cent in the figures shown in table 7.3.

7.5.3 Lifetime net costs

In order to derive estimates of this we must additionally make assumptions about the client's contribution. These assumptions are on a less certain basis than for gross costs, and depend on the client's resources.

The great majority of residents have no significant resources of their own. Their assessed income is based on Income Support and the Residential Care Allowance. It is likely these will continue for the whole of their stay, possibly with slight increases at the age of 75 and with increasing dependency.

In §7.4 we found that only 10 per cent of residents are assessed as having income significantly above these levels. In the absence of information to the contrary, we will assume that this income, most likely from a pension, will continue, so that the assessed client contribution based on income remains unchanged.

18 per cent of residents have resources in property. We will assume that these must be used to pay for care, until remaining assets are spent down to the threshold of £16,000 (the limit as at 1/4/96), whereon the local authority will take over responsibility. There are however two additional problems in assessing the contribution of this group.

- The value of property is unknown in 230 cases. This may be as much due to uncertainty about the legal position of the property as to doubts about its market value. (The average net value of property where known is £40,000).

- It is impossible to judge the likely client contribution that would be made once spend-down has occurred. Income Support entitlement will be affected by remaining capital. Note however that complete spend-down will only occur in a minority of cases of people with property capital at the outset.

These uncertainties create difficulties for the calculation of net life-time cost. We have therefore examined two slightly different sets of assumptions regarding capital.

- For people without capital, client contribution remains throughout their lifetime as it was assessed initially. This assumes income (if any) remains constant. For people with capital, it is assumed they will pay the total cost up to the limit of their capital (less

£16,000) and thereafter client contribution will be as originally assessed. For people with unknown capital, an average value of £40,000 is assumed.

- Client contribution remains throughout the lifetime as it was originally assessed.

These should represent the likely extremes with regard to client contribution from capital. With the first assumption, 260 (11 per cent) of the sample will be able to pay for their entire care, and the net cost to the local authority will be nil. With the second assumption, the local authority will contribute to everyone, though that contribution will be under £100 per week in 7 per cent of cases.

Table 7.4 shows the net unit costs under each of these assumptions, by type of care home. Taking account of capital, the mean lifetime net cost (over all types of home) would be £18,000 whereas if capital is not realised, it would be £20,000. This represents the likely range for the true net cost to social services, though once again note the high variability.

7.5.4 Predicting lifetime costs

Our final question concerns the predictability of the total costs of long-term care following first admission as a supported resident. This again concerns the costs to social services.

It follows from the arguments above that the factors at the outset which will affect the total cost will be those that influence life expectancy and the unit cost of care.

Because so few people leave the type of care to which they are first admitted, once a person is placed the total costs can be estimated from the weekly placement charge and the forecast average life expectancy. The two models developed in Chapter 5 for forecasting life expectancy, the first up to 30 months and the second beyond, can be used for this purpose though with the caveats expressed before. However, this is a little awkward and a future report of this survey will give simpler method of estimating life expectancy from circumstances at admission, suitable for this purpose.

The above method assumes the placement (in terms of type of bed) is known. Sometimes it might be of interest to estimate likely costs before a placement decision has been made. In this case we have to combine the estimated unit cost with the life expectancy. Slightly simpler is to construct a direct estimate of gross total lifetime cost by standard regression methods. This is shown in table 7.5, where the predictors are all the factors that have proved statistically significant in predicting either unit cost or life expectancy. Note that as is customary, this analysis is based on the logarithm of costs (because of the long-tailed

distribution). Table 7.6 shows how this can be used to estimate likely cost in a particular case.

A surprise here is that the predictability of lifetime costs is quite low – only 21 per cent of the variation in costs is 'explained' by factors at admission. This is partly because of the immense variability in costs, which was remarked on earlier. It is also partly because several of the factors that contribute to the need for a relatively high-cost intervention (in particular nursing care), are the very ones that are associated with low life expectancy. Overall, the prediction equation is counter-intuitive in that the factors that might seem to be least associated with need are the ones which result in highest lifetime costs. Thus low levels of dependency at admission will result in high costs. The final column of table 7.5 shows the magnitudes involved: for example, all else being equal a woman will cost 29 per cent more than a man, someone with a Barthel score below 5 at entry will cost well under half of someone with a score above 12. Local authority of origin is not statistically significant, due to the quite small numbers from London and the great variability, but had it been then the signs are of higher costs in Inner London.

7.6 Conclusion

Building on our analyses of mortality and with allowances for moves made after admission it is possible to predict the expected life-time costs after admission to a care home. Here we have focused on the gross and net costs to social services departments. Based on the findings up to 30 months after admission:

- The average gross lifetime cost to social services of a placement is predicted as £27,000 for initial admission to a nursing bed and £36,000 for a residential bed (1996 prices). There is tremendous variation in life-time costs and about 6 per cent will cost more than £100,000. These estimates depend on survival beyond 30 months, but are likely to be within 15 per cent of these figures.
- Net lifetime costs are harder to judge because of problems establishing the client contribution. The cost is much higher in local authority residential homes compared with other types of accommodation. Given the central forecast of survival it likely to be £31,000 - £34,000 for a placement in an LA home, £17,000-£19,000 in other residential homes, and £16,000-£18,000 in a nursing home.
- We recommend that gross lifetime costs should be estimated when required, from the initial weekly cost multiplied by expected survival, given by the prediction model in chapter 5. Despite changes following placement, this will still give a reliable estimate.

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- Where estimation of lifetime costs must be made prior to a placement decision, a prediction formula is given. However, those factors, which raise weekly costs (by leading to nursing rather than residential care), are precisely those that lower expected survival. The consequence is that while lifetime cost may be predicted from circumstances at the outset, the great variation means levels of prediction are low and such estimates cannot be expected to be accurate in individual cases.

After the 42 month wave is complete it will be possible to estimate survival a great deal more accurately and this will improve the estimation of lifetime costs.

Table 7.1: Reviews of charges for local authority funded residents in independent homes

(a) Regularly reviewed for:

	Private Homes %	Voluntary Homes %
Individual residents	17	15
All residents	68	72
Both of these	9	10
Not regularly reviewed	6	3
	100	100
Number	(327)	(143)

(b) Reviewed by:

	Private Homes %	Voluntary Homes %
The LA without the home	73	50
The LA together with the home	16	17
The LA with the home's managing organisation	9	25
Other	2	8
	100	100
Number	(n=322)	(n=141)

Table 7.2: Formula for imputing weekly charge (where unknown)

Estimated gross weekly charge is given by exp(z), where z is the sum of the following:

Constant	5.932
Local authority	
Shire	-0.210
Metropolitan	-0.276
Inner London	-0.083
Outer London	0.000
Placement	
Nursing home	0.011
LA Residential home	-0.107
Voluntary residential home	-0.203
Private residential home	-0.281
Dual registered (residential bed)	-0.268
Dual registered (nursing bed)	0.000
Barthel score	
0-4	0.031
5-8	0.034
9-12	0.022
13+	0.000

This formula is based on a log regression of 2054 cases where initial gross charge was known. Standard errors are not shown, but all factors are statistically significant. $R^2 = 0.68$.

For imputing assessed net weekly charge, £95 should be deducted in the case of residential homes and £105 in the case of nursing and dual registered homes.

Table 7.3: Gross lifetime cost of a local authority placement, by type of home to which originally admitted

(a) Mean, Median, Standard Deviation

	Median cost £	Mean cost £	Standard Deviation	N
LA residential home	30,963	42,889	43,331	211
Voluntary residential home	23,609	36,439	42,917	246
Private residential home	23,492	33,995	38,610	790
Dual registered home (residential bed)	23,700	32,117	32,350	92
Dual registered home (nursing bed)	12,383	30,187	41,620	70
Nursing home	14,404	27,248	36,738	976
Overall	17,290	28,362	34,868	2385

(b) Frequency

	Residential beds %	Nursing beds %
Under £1,000	5	11
£1,000 - £2,000	4	8
£2,000 - £5,000	8	14
£5,000 - £10,000	10	10
£10,000 - £20,000	17	14
£20,000 - £50,000	33	26
£50,000 - £100,000	16	12
Over £100,000	7	5
Total	100 (1339)	100 (1046)

(c) Means, with different assumptions about death rates beyond 30 months

	Residential beds	Nursing beds
High variant	£31,117	£24,819
Central forecast	£35,716	£27,445
Low variant	£41,897	£31,429

Table 7.4: Estimated net lifetime cost of a local authority placement, by type of home to which originally admitted

(a) Mean, Median, Standard Deviation (Allowing for Client's Capital)

	Median cost £	Mean cost £	Standard Deviation	N
LA residential home	16,238	30,743	36,666	211
Voluntary residential home	10,624	18,509	23,291	246
Private residential home	11,590	17,060	20,337	790
Dual registered home (residential bed)	12,698	16,758	17,267	92
Dual registered home (nursing bed)	5,216	17,387	23,265	70
Nursing home	5,902	16,027	25,914	976
Overall	9,921	17,996	25,082	2385

(b) Mean, Median, Standard Deviation (Not allowing for Client's Capital)

	Median cost £	Mean cost £	Standard Deviation	N
LA residential home	20,992	33,814	37,269	211
Voluntary residential home	11,702	19,934	23,642	246
Private residential home	13,236	19,035	20,754	790
Dual registered home (residential bed)	13,694	18,282	17,831	92
Dual registered home (nursing bed)	8,182	18,990	23,973	70
Nursing home	9,200	18,265	26,247	976
Overall	12,202	20,091	25,532	2385

Table 7.5: Model for predicting lifetime cost given circumstances on admission (prior to a placement decision)

Estimated gross lifetime cost is given by exp(z) where z is the sum of the following model coefficients:

	Model coefficient	Standard Error	F	df	Sig at 1% level?	Exp(z)
Constant	10.267	0.325	7346.37	1	Yes	
Area of origin			1.57	3	No	
Shire county	0.000	-				1.00
Metropolitan district	0.001	0.069				1.00
Outer London	0.007	0.156				1.01
Inner London	0.316	0.149				1.37
Gender			12.57	1	Yes	
Man	0.000	-				1.00
Woman	0.257	0.073				1.29
Age at admission			15.97	2	Yes	
65-74	0.000	-				1.00
75-84	-0.231	0.105				0.79
85+	-0.526	0.106				0.59
Diagnosed illness on entry						
Respiratory	-0.370	0.091	16.43	1	Yes	0.69
Malignancy	-1.054	0.120	77.55	1	Yes	0.34
Barthel Score on entry			32.87	3	Yes	
0-4	-0.963	0.100				0.38
5-8	-0.264	0.089				0.77
9-12	-0.441	0.085				0.64
13+	0.000	-				1.00
MDS Cognitive Scale			0.37	2	No	
Intact	0.000	-				1.00
Mild impairment	-0.045	0.087				0.96
Severe impairment	-0.081	0.094				0.92
Source of admission			4.99	3	Yes	
Private household	0.000	-				1.00
Care home	0.287	0.147				1.33
Hospital	-0.150	0.071				0.86
Other	-0.545	0.254				1.72

$R^2 = 0.21$.

Table 7.6: Illustrative calculation of predicted gross lifetime cost to social services of admitting someone in particular circumstances

	Coefficient from table 7.5
Constant	10.267
Living in shires	0.000
Woman	0.257
Aged 75-84	-0.231
No diagnosed medical conditions	0.000
Barthel score 0 – 4	-0.963
Mild cognitive impairment	-0.045
Admitted from hospital	-0.150
Total score	9.135

Estimated gross lifetime cost = exp(9.135) = £9,274

References

Askham, J., Henshaw, L. and Tarpey, M. (1995) *Social & Health Authority Services for Elderly People from Black & Minority Ethnic Communities*, HMSO, London.

Bebbington, A., Brown, P., Darton, R., Miles, K. and Netten, A. (1998) *Survey of Admissions to Residential and Nursing Home Care. 18 Month Follow-Up*, PSSRU Discussion Paper No. 1428/2, Personal Social Services Research Unit, University of Kent at Canterbury.

Bebbington, A., Brown, P., Darton, R., Miles, K. and Netten, A. (1999) *Survey of Admissions to Residential and Nursing Home Care. 30 Month Follow-Up,* PSSRU Discussion Paper No. 1537, Personal Social Services Research Unit, University of Kent at Canterbury.

Boaz, A., Hayden, C. and Bernard, M. (1999) *Attitudes and Aspirations of Older People: A Review of the Literature*, Department of Social Security Research Report No. 101, Corporate Document Services, Leeds.

Cm 4169 (1998) *Modernising Social Services. Promoting Independence, Improving Protection, Raising Standards*, The Stationery Office, London.

Collin, C., Wade, D.T., Davies, S. and Horne, V. (1988) The Barthel ADL Index: A Reliability Study, *International Disability Studies*, **10**, No. 2, 61-63.

Darton, R. and Brown, P. (1997) *Survey of Admissions to Residential Care. Analyses of Six Month Follow-Up*, PSSRU Discussion Paper No. 1340, Personal Social Services Research Unit, University of Kent at Canterbury.

Donaldson, L.J., Clayton, D.G. and Clarke, M. (1980) The Elderly in Residential Care: Mortality in Relation to Functional Capacity, *Journal of Epidemiology and Community Health*, **34**, 96-101.

Granger, C.V., Dewis, L.S., Peters, N.C., Sherwood, C.C. and Barrett, J.E. (1979) Stroke Rehabilitation: Analysis of Repeated Barthel Index Measures, *Archives of Physical Medicine and Rehabilitation*, **60**, 14-17.

Laing and Buisson (1999) *Care of Elderly People: Market Survey 1999*, 12th ed., Laing and Buisson, London.

Morris, J.N., Fries, B.E., Mehr, D.R., Hawes, C., Phillips, C., Mor, V. and Lipsitz, L.A. (1994) MDS Cognitive Performance Scale, *Journal of Gerontology: Medical Sciences*, **49**, No. 4, M174-M182.

Murray, U. and Brown, D. (1998) *They Look After Their Own, Don't They? Inspection of Community Care Services for Black and Ethnic Minority Older People*, Department of Health, London.

Netten, A., Bebbington, A., Darton, R., Forder, J. and Miles, K. (1998*) 1996 Survey of Care Homes for Elderly People. Final Report*, PSSRU Discussion Paper No. 1423/2, Personal Social Services Research Unit, University of Kent at Canterbury.

Netten, A., Darton, R., Bebbington, A. and Brown, P. (1999) *Residential or Nursing Home Care? Appropriateness of Placement Decisions*, PSSRU Discussion Paper No. 1480, Personal Social Services Research Unit, University of Kent at Canterbury.

Netten, A. and Dennett, J. (1996) *Unit Costs of Health and Social Care 1996*, Personal Social Services Research Unit, University of Kent at Canterbury.

OPCS (1993) *1991 Census. Report for Great Britain (Part 1)*, CEN 91 RGB, HMSO, London.

Patel, N. (1999) Black and Minority Ethnic Elderly: Perspectives on Long-Term Care, Research Report for The Royal Commission on Long Term Care (1999) *With Respect to Old Age: Long Term Care - Rights and Responsibilities*, Cm 4192-II/1, Chapter 9, The Stationery Office, London.

Royal Commission on Long Term Care (1999) *With Respect to Old Age: Long Term Care - Rights and Responsibilities*, Cm 4192-I, The Stationery Office, London.

Schuman, J. (1999) The Ethnic Minority Populations of Great Britain - Latest Estimates, *Population Trends* 96, Summer 1999, 33-43.

Simpson, S. (1996) Non-response to the 1991 Census: The Effect on Ethnic Group Enumeration, in *Ethnicity in the 1991 Census. Volume 1, Demographic Characteristics of the Ethnic Minority Populations,* D. Coleman and J. Salt (eds), HMSO, London.