

CHARACTERISTICS OF ELDERLY PEOPLE WITH A MENTAL HANDICAP LIVING IN A MENTAL HANDICAP HOSPITAL: A DESCRIPTIVE STUDY

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Introduction

Improvement in quality of medical care has led to increasing longevity in most industrial countries. In Britain, for example, it is estimated that there will be a 23% increase in the number of those aged 75 years or more between 1976 and 1996. During the same period for those above 85 years of age the rise is estimated to be about 42% (Walker, 1981). Similar figures for people with mental handicap are not estimated. However, tentative conclusions are possible.

Morbidity and Mortality Issues

People with mental handicap (PMH) are more susceptible to illness and the impact of advances in medical care has been obvious. Fryers (1984) reported

a death rate of only 10% among children with Down syndrome compared with that of 50% in earlier studies (Oster, 1953; Record and Smith, 1955; Carter, 1958; Hall, 1964). Furthermore, a study estimated that the death rate for PMH was about 13 times that of a non-handicapped population (Conley, 1973). A study in the late twenties (Dayton *et al.*, 1932) reported that 28% of the children assessed at 10 years had survived up to 60 years. Balakrishnan *et al.* (1976) showed that in the early seventies the corresponding rate of those who survived into old age was about 46%. The estimates of Forssman and Akesson (1970) that individuals with mild MH had a mortality of 1.7 times and for those with severe MH, a comparable figure of 4.1 times that of the general population would appear not to have changed despite recent advances in medical care.

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Richards and Sylvester (1969) examined the mortality trends in the mentally handicapped population over the age of 5 years, resident in a long stay mental handicap hospital over a period of 40 years. The mean age at death for males rose sharply during the 40 year period and up to 50 years of age there was no difference between the age at death of people with Down's syndrome and those without Down syndrome of equivalent mental age ranges. After 50 years of age the mortality of people with Down syndrome rose sharply. Richards and Siddiqui (1980) followed the mortality age trend for a further 10 year period in the same institution and found an aging population in the hospital which was accounted for by the non-admission of children and younger age people, and increasing rates of discharges of younger residents of the hospital. Studies from the Stoke Park group of hospitals, Bristol by Carter and Jancar (1982, 1983) confirmed these findings and in particular that non-infection causes predominated as reasons for mortality. They also found an increase in the average age of death from 14.9 years to 58.3 years for males and from 22 years to 59.8 years for females over the 50 year period between 1930 and 1980. Studies of unexpected death in PMH (Carter and Jancar, 1984; Roy and Simon, 1987; Kent, 1990) have shown that in many cases there were congenital anomalies of gastrointestinal and cardiovascular systems.

Elderly PMH (EPMH) have dual disadvantages of old age and mental handicap (Sweeney and Wilson, 1979) and this aspect of community care

requires further study as responsibility of providing the primary health care is largely dependent on the training of carers and family practitioners in the community. A recent study from Denmark (Dupont and Mortenson, 1990) investigated the causes of death and assessed the "avoidability" of these causes. They concluded that the "avoidable mortality risk of dying" was four times higher in the severely mentally handicapped population than in the general population in Denmark. The above studies and that of McCurley *et al.* (1972), Miller and Eyman (1978), Tait (1983) and Eyman *et al.* (1987) have shown that PMH have an increasing life span. For people with Down syndrome, lower levels of IQ were associated with higher mortality as shown in a study by Heaton-Ward (1968). The causes of death were infections, leukaemia and congenital heart diseases. However, other studies over the years have shown a trend towards increasing life span for this group of people (Forssman and Akesson 1965; Richards and Sylvester, 1969; Richard and Siddiqui, 1980; Carter and Jancar, 1982).

Most of the studies, discussed above, relate to people who were in large institutions and similar studies conducted in the community have concluded that the differences were entirely due to the nature of service provisions in the community. McCurley *et al.* (1972) found that mortality rates for residents in an institution were higher than that of those who were in various community settings but when corrections were made for the relative absence of an older comparable

population the differences were not significant. Miller and Eyman (1978) studied residents in community and institutional settings in Southern California, USA, and found higher rates of mortality, as expected, in convalescent hospitals but the rates were higher in residential institutions when compared to other community settings. The conclusion from the two studies is that when client characteristics are compared the mortality rates would appear to be the same for both the community and institutional settings.

Community Service Issues

Community services have not developed in keeping with the increase in the number of EPMH. In USA, for example, most state or private agencies had no major plans in the late seventies for provision of services for this group of people (Sweeney and Wilson, 1979; Janicki *et al.*, 1984). In UK, the white paper "Better services for the mentally handicapped" (DHSS, 1971) gave guidelines to local service and health authorities in establishing services in the community in preference to institutional service provisions. However, the perception of those in related services is that relevant services have not been established adequately (Wynn-Jones, 1984). An example is a study conducted in Northern Ireland which found that only 23% of EPMH over the age of 65 years who were in the community were known to the local services (Mackay and Elliott, 1975).

Defining the Age Limits

Evidence of premature aging associated with Down syndrome (Dalton and Crapper, 1977) and the observation that other EPMH with severe MH have various physiological and neurological impairments from their early lives (Sweeney and Wilson, 1979) create problems in defining an age criterion for old age in EPMH. The suggested age limits range from lower than that for general population (Hamilton and Segal, 1975), 55 years and over (Daniels, 1979), 50 years and over (Janicki, 1984; Selzer, 1984), 45 years (Thomae and Fryers, 1982) and to the lowermost level of 40 years (Fancolly and Clute, 1975; Kriger, 1975). However, others suggest that similar age boundaries of 60 to 65 years as applied to non-handicapped populations can be used to estimate the service provisions for EPMH (Ballinger, 1978; Rowitz, 1979).

This paper describes the findings of a survey of the characteristics of people above the age 65 years resident in Stalington Hospital (SH), a long stay mental handicap hospital situated in the moorlands of the West Midlands, in the UK. The purpose of the survey was to assess the extent of problems involved in resettling these people in the community, given the proposed reduction in the total number of beds in the hospital, from 300 to 150, within the next two to three years.

Method

All long stay residents above the age of 65 years as on 1.4.1991 were

included in the study. Information was obtained from medical and nursing case notes and from the minutes taken during annual reviews attended by members of the multidisciplinary team involved with the care of the residents. Details regarding date of birth, date of admission, duration of stay in the hospital, medical conditions and medication were collected from the medical notes. Contact with relatives and day activity details were taken from the nursing notes. Disabilities, skills and behavioural problems were recorded using the Disability Assessment Schedule (Holmes *et al.*, 1982) (DAS). DAS, a structured interview schedule, was scored after interviewing either the key worker or the senior nurse manager of the ward who knew the resident for more than a year. Information about whether or not the resident was suitable to be placed in the community, as per evaluation by the team, and whether a placement had been identified for the resident was collected mostly from the notes of the annual review meetings. Data was analysed as a group, the items in the DAS were analysed as raw scores without using the summary score method as calculated by Wing (1989). Psychiatric diagnosis and level of mental handicap were made in accordance with the glossary of the ninth revision of International Classification of Diseases (W.H.O., 1978). The items in the personal characteristics check list and DAS are given in Appendix A.

The collected information was analysed in four different ways; as a group, by sex, by degree of mental handicap and by age ranges (years 65 to 69, 70

to 74, 75 and over) and where relevant Chi-Square tests were used to compare the groups. The results, where possible, were compared with the information given in the previous publications, particularly with those provided by Day (1987) in his study of EPMH at Northgate Hospital (NH) situated in the north eastern part of England.

Results

Of the total population of 300 residents in the hospital at the time of the study 59 (19.6%) were found to be aged 65 years and above. This hospital has a catchment area population of 750,000 and this gives a rate of 8.6 (EPMH in the hospital) per 100,000.

Personal and DAS items were analysed in four different ways as mentioned in the methodology section. As there were no significant differences when analysed by sex, by age range and by degree of mental handicap, except in a very few items, the results obtained by total group analysis are given below.

There were 23 (38.9%) male and 36 (61.1%) female residents. The average age of the residents above 65 years of age was 71.1 (min. 65, max. 81, s.d. 4.8). The average age for males was 69.9 years (min. 65, max. 81, s.d. 4.63) and for females 72.13 years (min. 65, max. 81, s.d. 4.72). 77.9% of the sample were in the 65-74 year age group. Average duration of stay in the hospital was 36.5 years (min. 2, max. 61 years, s.d. 16.5). 86.4% were resident in the hospital for more than 10 years. All the residents were of caucasian ethnic origin. None had a living parent. More

than two thirds (67.8%) had a living sibling. 55.9% had no contact with relatives and 76.2% did not have any visits from or visited any other people during their stay in the hospital. It was considered that 67.8% were appropriately placed in the hospital during the annual review evaluations, and 23.7% of the EPMH were considered suitable for discharge but no specific plans were made. Suitable residential places had been identified for only 8.4%.

Aetiology of mental handicap was known in only 13.5% and family history of mental handicap was present in 8.4%. 71.1% had chronic medical conditions of more than 6 months duration. Only 10% did not receive any medication and 45.7% of the patients were on some form of combination of medications. 15.1% had epilepsy. 77.9% had moderate to severe mental handicap as recorded in the case notes.

Disabilities and skills

69.4% were mobile without help. 70 to 80% were continent (wetting, soiling) and 64.4% used a toilet on their own. 84.7% were able to feed themselves; 64.4% were able to wash themselves without help. However, only 13.5% were able to dress themselves without help (TABLE I). 64.4% did not require any practical aids. The breakup of figures, for the use of practical aids, was as follows: Wheel chairs (6.7%), eating aids (3.3%), walking aids (8.4%), incontinence pads (10.1%) and other aids (6.7%). 23.7% had no day time activity outside the ward. 84.8% of EPMH received disability

allowance and only 5% had mobility allowance.

Only 6.7% could read and 3.3% could write a short letter. 18.6% could go to the hospital shop to make a simple purchase. 45.7% required no supervision during domestic work, 28.8% could do simple handicraft products and only 8.4% had better occupational skills (TABLE II).

91.5% had normal vision and 88.1% had normal hearing. Only 67.8% were able to communicate by speech alone. 44% were able to understand about events and information outside their immediate experience. Only 35.5% were able to converse about their own personal experiences. 62.7% had pronunciation sufficient and good enough to be understood by people not familiar with them (TABLE III).

Behavioural management problems

30.5% showed physical aggression and another 16.9% were potentially aggressive. 45.7% showed temper tantrums and 23.7% had socially objectionable behaviours. Attention seeking (20.3%) and screaming (18.6%) were the other problem behaviours. It was estimated that about one third from this group would need long term input from a specialist behaviour modification nursing team (TABLE IV).

42.3% made appropriate social interactions and the rest were socially impaired with varying levels of interaction deficits (TABLE V). 3 to 15.2% showed some form of stereotyped behaviour and 20.3% showed stereotyped

behaviours when unoccupied. Elaborate stereotyped routines sufficient to disrupt their day activity were seen in 10.1% only. 15.1% had immediate echolalia and 20.2% had delayed echolalia. Repetitive speech was seen in 38.9%. 59.3% had no symbolic activity and 50.8% had no imaginative play (TABLE VI).

Results by sex, degree of mental handicap and age ranges

Analysis by sex did not show any statistically significant differences in most of the items in the personal characteristics category except for placement in future ($p = 0.001$) where 86% of females did not

TABLE I

Disability Assessment:		n = 59		%					
I. Mobility									
1. Non-mobile/needs help		10		16.9					
2. Needs help upstairs		1		1.6					
3. Needs help/blind,epilepsy		2		3.3					
4. Fully mobile/wheel chair		5		8.4					
5. Walks unaided		41		69.4					
II. Continance									
		Nights				Days			
		Wetting		Soiling		Wetting		Soiling	
		N	%	N	%	N	%	N	%
1. 5 to 7 times/week		10	16.9	2	3.3	9	15.2	4	6.7
2. 3 to 4 times/week		1	1.6	-	-	1	1.6	-	-
3. 2 times/week		2	3.3	4	5.0	4	6.7	5	15.2
4. Once/week		5	8.4	3	5.0	4	6.7	4	6.7
5. Never		41	69.4	50	84.7	41	69.4	46	77.9
Toileting habits									
		N	%						
1. Needs help daily		17	28.8						
2. Asks to go		4	6.7						
3. Goes alone		38	64.4						
Self-help									
		Feeding		Washing		Dressing			
		N	%	N	%	N	%		
1. Not at all		2	3.3	5	8.4	8	13.5		
2. With help		7	11.8	16	27.1	26	44.0		
3. Without help		50	84.7	38	64.4	8	13.5		
4. Can tie shoe laces		-	-	-	-	17	28.8		

require placement outside the hospital. Analysis of items in DAS by sex showed no significant statistical differences in most items except for items of self injury ($p = 0.031$), temper tantrums ($p = 0.054$), objectionable personal habits ($p = 0.005$) and sexual problems with social awareness ($p = 0.042$). These behaviours were mostly seen in males. Analysis by degree of mental handicap did not show statistically significant differences in all the items in personal characteristics mentioned above except that those in mild

and borderline category had regular day time activity ($p = 0.053$). Analysis of items in DAS, by degree of mental handicap showed statistically significant differences in reading ($p = 0.006$), writing ($p = 0.004$), counting money ($p = 0.011$), domestic skills ($p = 0.0018$), occupational skills ($p = 0.003$) and symbolic activity ($p = 0.002$) with those in mild to borderline category scoring well in all the above items of skills. Analysis by age ranges 65 to 69 years, 70 to 74 years and 75 years and above, did not show any significant

TABLE II

Skills	N	%					
a. Reading							
1. No understanding of written word	34	57.6					
2. Can recognise his own name	13	22.0					
3. Can match words to pictures	3	5.0					
4. Can recognise upto 10 words	3	5.0					
5. Can read/understand first books	1	1.6					
6. Can read/understand simple books	1	1.6					
7. Can read	4	6.7					
b. Writing							
1. None	37	62.7					
2. Write letters by copying	14	23.7					
3. Write words by copying	-	-					
4. Write letters without copying	3	5.0					
5. Write simple words/without copying	2	3.3					
6. Write 12 or more words/without copying	1	1.6					
7. Write short letter	2	3.3					
c. Counting/money							
1. Nothing/can say 1 2 3	27	45.7					
2. Sort 4 spoons, 3 sheets, 5 plates	21	35.5					
3. Can go to a shop	11	18.6					
		d. domestic skills		e. Handicrafts		f. Occupational skills	
		N	%	N	%	N	%
1. None	17	28.8	24	40.6	32	54.2	
2. Supervision needed	14	23.7	16	27.1	5	8.4	
3. No supervision	27	45.7	17	28.8	5	8.4	

TABLE III

Vision, Hearing, Communication				
	Vision		Hearing	
	N	%	N	%
1. None/almost	4	6.7	2	3.3
2. Poor	1	1.8	4	6.7
3. Normal	54	91.5	52	88.1
Communication				
	N		%	
c. Method of communication				
1. Little/nothing/meaningless	2		3.3	
2. A few sounds/gestures	2		6.7	
3. Mostly gestures	8		13.5	
4. Mixtures-speech/gestures	7		11.8	
5. Speech alone	40		67.8	
d. Understanding communication				
1. Little/nothing	-		-	
2. Few simple commands	8		10.1	
3. Fair range/practical needs	8		13.5	
4. Understands/personal needs	19		32.2	
5. Understands/outside information	26		44.0	
e. Using communication				
1. Little/nothing	6		10.0	
2. Few words/signs	3		5.0	
3. Words/signs/practical needs	9		15.2	
4. Words/signs/personal experience	20		33.9	
5. Can converse/personal experience	21		35.5	
d. Pronunciation				
0. Not enough speech	7		11.8	
1. Difficult to understand	7		11.8	
2. Understood/by close acquaintances	6		10.1	
3. Understood/by others	37		62.7	

TABLE IV

Behavioural problems	Severe		Lesser		Not Problem		Potential	
	N	%	N	%	N	%	N	%
Physically aggressive	18	30.5	5	8.4	26	44.0	10	16.9
Destructive	6	10.1	2	3.3	48	81.3	3	5.0
Overactive	7	11.8	5	8.4	46	77.9	1	1.6
Seeks attention	12	20.3	5	8.4	40	67.8	2	3.3
Self injury	6	10.1	3	5.0	50	84.7	-	-
Wanders/runs away	5	8.4	-	-	52	88.1	2	3.3
Screams	11	18.6	6	10.1	40	67.8	2	3.3
Temper tantrums	27	45.7	7	11.8	20	33.9	5	8.4
Disturbs at night	5	8.4	1	1.6	48	81.3	5	8.4
Objectionable behaviour	14	23.7	5	8.4	39	66.1	1	1.6
Scatters/throws objects	6	10.1	3	5.0	49	83.0	1	1.6
Anti-social	5	8.4	6	10.1	48	81.3	-	-
Sexual delinquency	5	8.4	1	1.6	50	84.7	3	5.0

differences in the items of personal characteristics and there were no significant differences in all the items of DAS except for attention seeking behaviour ($p < 0.05$) which was common in younger age groups.

Discussion

General Issues

The overall number of EPMH in mental handicap hospitals has increased in recent years (TABLE VII) and they form a much lower but increasing proportion of the total hospital population. This could be due to the high mortality of those with severe or profound mental handicap. There were more EPMH with severe MH in SH than in NH (Day, 1987), and 45.7% of EPMH in this study had severe mental handicap which indicates that although the survival rate is low, some people from this group do survive. Comparison of duration of stay in years, by degree of mental handicap and age range, shows that EP with severe MH have stayed for similar periods in each category of age range (TABLE VIII). Perhaps, this rate of survival could be

because of the intensive nursing and regular medical care provided in the hospital setting. Also, the trend is that EPMH are only seen as out patients in the community (Ballinger, 1979) and are not admitted for long term residential care to mental hospitals. With the trend of resettling those with lesser levels of problems, it is likely that the proportion of EPMH in the hospital, with relatively higher levels of problems, will continue to increase.

The mean duration of stay in the hospital was 36.5 years (min. 2, max 61, SD 16.9). Comparison by age shows that females were slightly older than males (TABLE IX) and females in each category of mental handicap had spent longer durations (TABLE VIII). The EPMH in SH and NH were compared, by percentage figures of sex and degree of mental handicap breakdown. In each band there were differences suggesting that there is a variable pattern of EPMH population in these hospitals (TABLE IX).

Contact with family

Most of the EPMH had spent a greater part of their life in hospital care. None were married or had lived on their

TABLE V

Quality of Social Interaction	N	%
1. Does not interact/aloof/indifferent	6	10.1
2. Interacts/to obtain needs	4	6.7
3. Responds/physical contact	1	1.6
4. Responds/passively	7	11.8
5. Peculiar approaches	6	40.6
6. Unhappy without company	3	45.7
7. Interacts appropriately	7	11.8
8. Makes social approaches	25	42.3

TABLE VI

Stereotyped behaviour	N	%
a. Choice of activities		
1. Nothing	26	44.0
2. Sometimes nothing	7	11.8
3. Always stereotyped	2	3.3
4. Sometimes stereotyped	3	5.0
5. Sometimes constructive	9	15.2
6. Always constructive	12	20.3
b. Simple stereotypes		
1. Marked when unoccupied	12	20.3
2. Present, minor pattern	2	3.3
3. Minimal or none	45	76.2
c. Elaborate routines		
1. Elaborate routines	6	10.1
2. Minor routines	12	20.3
3. Minimal or none	41	69.4
Echolalia, Repetitive speech	N	%
a. Immediate echolalia		
0. No speech	6	10.1
1. Echolalia, daily	5	8.4
2. Less than daily	4	6.7
3. Rarely/never	43	72.8
b. Delayed echolalia		
0. No speech	6	10.1
1. Echolalia, daily	7	11.8
2. Less than daily	5	8.4
3. Rarely/never	41	69.4
c. Repetitive speech		
0. Not enough speech	8	13.5
1. Marked repetitive speech	8	13.5
2. Some tendency	15	25.4
3. Little/nothing	28	47.4
Symbolic Activities	N	%
a. Imaginative, pretend play		
1. No imaginative play	30	50.8
2. Beginning of play	13	22.0
3. Pretend play	16	27.1
4. Not known	-	-
b. Repetitive symbolic activities		
0. No symbolic activities	35	59.3
1. Marked repetitive activities	7	11.8
2. Some tendency	-	-
3. Minimal/no problem	17	28.8
4. Not known	-	-

TABLE VII
Surveys of elderly people with mental handicap, in UK

	Northern Hospital	Strathmartine Hospital	Meanwood Hospital	Northgate Hospital	Stallington Hospital
Source	Mackay & Elliott (1975)	Ballinger (1978)	Spencer (1978)	Day (1987)	-
Survey date	1971	1977	1978	1984	1991
Population surveyed	Community/Hospital	Hospital	Hospital	Hospital	Hospital
Lower age limit	60 years	65 years	65 years	65 years	65 years
No. of people	209 (77% in Hospitals)	38	64	99	59
% of mentally handicapped population	4.4% (7.3% in Hospitals)	6.5%	11.6%	19%	19.6% (in hospital)
F:M ratio	1:1 (Hospital) 1.2:1 (Community)	2:1	2:1	2:1	1.56:1
Moderate/Mild Mental Handicap	35% Hospitals 44% Community (IQ 50-75)	82% (IQ 36-85)	56% (IQ 40-69)	65% (IQ 35-70)	42.3% (IQ 35-70)
65-74 years	55% (65-69 years)	79%		68%	77.9%
Duration hospital/institutional care	-	95% over 6 years	85% over 20 years	94% over 10 years	86.4% over 10 years

TABLE VIII
Duration of stay by degree of mental handicap and sex

Degree of Mental handicap	Male					Female									
	N	Mean	Min	Max	SD	N	Mean	Min	Max	SD					
Total	23					36									
Borderline	4	38.7	31	60	14.1	3	39.6	33	49	8.3					
Mild	3	25.3	4	45	20.5	3	46.6	40	50	5.7					
Moderate	10	37.7	4	61	18.5	9	39.2	13	50	14					
Severe	6	28.6	4	51	20.6	21	36.3	2	60	18					
Duration of stay by Degree of mental handicap and age ranges															
Degree of Mental handicap	65 to 69 years					70 to 74 years					75 years and above				
	N	Mean	Min	Max	SD	N	Mean	Min	Max	SD	N	Mean	Min	Max	SD
Borderline	1	32	32	32	-	2	35	33	37	2.8	4	43	31	60	14
Mild	2	38.5	27	50	16.2	3	29.6	4	15	22.3	1	50	50	50	-
Moderate	7	31.7	4	51	18.6	9	39.3	13	50	14.1	3	51.3	43	61	9.07
Severe	14	35.4	2	53	19.03	7	30.5	3	60	21.09	6	37.5	23	60	16.6

NOTE: N = number of EPMH
Mean, Min, Max = in number of years

TABLE IX

Sex and Age in years													
Sex	N		Average		Min.		Max.		SD				
Male	23		69.69		65		81		4.63				
Female	36		72.13		65		81		4.72				
Age and severity of mental handicap													
Northgate Hospital (Day 1987)						Stallington Hospital (- 1990)							
		65-69 years		70-74 Years		75 years +		65-69 years		70-74 years		75 years +	
		N	%	N	%	N	%	N	%	N	%	N	%
		34		35		30		24		22		13	
Severe	12	35	12	34	10	33	14	58	7	33	6	76	
Moderate	11	32	8	17	8	27	7	29	9	43	3	42	
Mild	10	29	16	45	10	33	2	8.3	3	14	1	11	
Borderline	1	3	1	2	2	6	1	4.2	2	9.5	4	71	
Sex and severity of mental handicap													
Northgate Hospital (Day 1987)						Stallington Hospital (- 1990)							
		Males		Females		Total		Males		Females		Total	
		N	%	N	%	N	%	N	%	N	%	N	%
		33		66		99		23		36		59	
Severe	13	39	21	32	34	34	6	17	21	58	27	75	
Moderate	7	21	18	27	25	25	10	13	9	25	19	38	
Mild	13	39	23	35	36	36	3	43	3	8.3	6	51.3	
Borderline	0	-	4	6	4	4	4	26	3	8.3	7	34.3	

own before admission to the hospital. Senior nurses of the hospital who remember the events leading to admission of some of the EPMH recall that a number of EPMH were admitted for social reasons and that some of the admissions were for "reasons of morally defective behaviour". This could explain the higher levels of abilities and the number of those classified as having borderline MH found in this study. As in Day (1987), the family contact was restricted to visits by siblings as none in this study had a surviving parent. On the whole, the

percentage of those who had contact with relatives or others was similar to that given by Day (1987).

Day time activity

In the present study 23.7% had no "day activity" during the day. Lack of meaningful day activity is sharply criticized by Wynn-Jones (1984) but further work is required to assess the resources in the hospital as staff ratios and adaptation of the ward structure in these wards may have some implication for the lack of day care.

Physical and Mental Health Issues

The physical health care needs of EPMH at SH are provided by a team of clinical medical assistants and by two trainee psychiatric registrars. This is in addition to the three consultants in psychiatry who are on call and are available for consultation. The night on-call cover is shared by general practitioners from the local group practice firms. On each working day of the week the three non-consultant doctors visit each ward and conduct surgeries. In addition, each resident gets a full physical and psychiatric check up once a year as part of an annual multidisciplinary clinical review of all residents. For secondary care the residents are referred to the local district general hospital. As all the medical consultations are done on a daily basis it was not possible to quantify the consultation rates with any justifiable accuracy for comparison with the figures given by Day (1987).

EPMH in SH and NH had similar numbers of chronic medical conditions but the percentages of individual system disorders were generally higher in SH group. Furthermore, the group in SH had higher psychiatric morbidity (30.5%) when compared to similar figures given for NH (TABLE X). Unlike in NH group, those in SH had more behavioural problems, with a full range of behavioural problems as given in DAS. The EPMH in Ballinger's study (Ballinger, 1978) did not appear to be markedly less disturbed than the rest of the population in their hospital. It would appear that over the

years those with generally higher levels of behavioural problems have accumulated in the hospital. As no particular screening method for detecting dementia was used in this study it was not possible to give the comparable figures. Day (1987) reports that 6% of EPMH in his study had dementia. In conclusion, it would appear that on most parameters the SH group had higher indices of morbidity. This is in conformity with the conclusion drawn by Framer *et al.*, (1990) who found higher levels of disabilities and behavioural problems in mental handicap hospital residual population.

Resettlement Issues

It should be noted that although the higher percentages of mobility (70%) and continence (70-80%) show a lower level of dependency, these figures could rapidly change in view of the advanced age of these residents. This would effectively put enormous strain on local agencies if such an allowance is not made in advance, in service planning and provisions.

Problems in community care for EPMH

At present very few studies have addressed the issue of community care for EPMH in the UK. (Hogg *et al.*, 1988). The consultation rates for psychiatric services is low (Ballinger, 1979) but these studies do not provide information about those who were not referred for specialist assessments and care. Studies conducted elsewhere are not entirely relevant to the recent changes that have

TABLE X
Psychiatric disorders and medical conditions

Psychiatric Disorders	Stallington Hospital (N = 59)		Northgate Hospital (N = 99)	
Schizophrenia	2		2	
Affective illness (MDP)	4		5	
Depression, reactive	9		1	
Dementia	3		6	
Non specific	-		1	
Total	18		15	
Number of Medical Conditions	Stallington		Northgate	
	N	%	N	%
One condition	20	33.8	-	33
Two conditions	19	32.3	-	26
Three or more	5	8.4	-	17
Average per person	1.65		1.92	
Number of Medical Conditions	Stallington N = 59		Northgate N = 99	
	N	%	%	
Cardio-respiratory	16	27.1	24	
Alimentary	13	22.0	6	
Hormonal	9	15.2	7	
CNS/Palsy/Etc.	6	10.1	-	
Genito-Urinary	4	6.7	13	
Skin	4	6.7	6	
Eye/Cataracts/Etc.	3	5.0	-	
Skeletal	3	5.0	-	

taken place in the structure and functions of the National Health and Social Services in the UK but provide information about the nature of problems faced by EPMH in the community.

A large study in Canada (Badry *et al.*, 1988), which compared service needs of community and institution based EPMH found that those in the community (i.e. within lodges, extended care centres, nursing homes and auxiliary hospitals) had significantly higher levels of health impairments e.g., paralysis,

neurlogical and musculoskeletal impairments, oedema and obesity. These problems can be grouped as "geriatric" medical problems commonly seen in elderly people. However, as expected, these people showed higher levels of community living skills, for example laundry, banking, public transportation, shopping, telephone usage and were in several of the community based activities coordinated by the local services. The picture seen in our study in so far as the medical problems are concerned is very

similar although the low levels of domestic and related skills, as expected, are low. This is in keeping with the lack of opportunities for exercising the community skills in a hospital setting.

Masskant and Haveman (1989) who studied 79 group homes in two provinces of the Netherlands between 1986-1988 found a positive relationship between age and sensory handicaps and chronic diseases. They made a number of suggestions with regard to community care for this particular group of people. They suggest, in particular, that residences have to be prepared for a shift in character of their residents and that local services should plan for the possible admission of elderly residents within the next five years. They also make a number of comments on staff training, aimed at increasing skills related to geriatric and gerontological skills. As retired residents spend much of their time at home and as this "at-home-resident" population increases, day time activities to reduce boredom and inactivity should be given importance to prevent clinical depression.

Many elderly parents provide care at home to their middle aged sons and daughters with mental handicap. In many instances the elderly parent is looked after by the person with mental handicap resulting in mutual dependency. In some instances the elderly parent is a single parent well into the geriatric age range. In these families the geriatric residential need is two fold. Within a few years both the parent and the son/daughter will need residential care and the impression of several care groups is

that local social service establishments in the UK are relatively slow in developing services to this group and a number of practical suggestions have been put forward by CAMR (1982), as highlighted by Wynn-Jones (1984).

Relocation of EPMH

Relocation syndrome is an adjustment disorder (DSM-III-R 1987) and is described in the literature as the emergence of a cluster of symptoms, as the direct consequence of an involuntary and unprepared resettlement of people from one location to another location. The symptoms can include decreases in adaptive behaviour, increase in maladaptive behaviour, pessimism, depression, withdrawal, weight loss, increased rate of physical illnesses, confusional state and increased mortality rates (Holtom *et al.*, 1990). Lishman (1980) refers to catastrophic reaction, which is commonly seen in people with cerebral disorders who are exposed to changes beyond their capacity to cope, as "when taxed beyond his ability, however, he may become evasive and sullen, or react abruptly with an explosion of primitive affect such as anger, anxiety or tears". Deinstitutionalism of people with MH is described by Coffman and Harris (1980) in terms of a "transition shock" and as a process of culture/reverse culture shock with features of cue problems, value discrepancies and adjustment problems involving severe emotional and physical responses.

Deinstitutionalisation of people with mental handicap leads to changes in adaptive behaviours, activity levels,

social interaction behaviours and quality of life. There is evidence that there are substantial gains in adaptive behaviour, quality of life, increase in meaningful day time activity levels with long term improvements in social and community integration after an initial period of disruptive behaviours in a minority (Allen, 1989). In a few people this may be a persistent behaviour leading to readmission to an institution (Hemming *et al.*, 1981; Rawlings, 1985; Hemming, 1986). However, after an extensive review of the effects of relocation, Allen (1989) concludes that " 'Transition shock' appears to be a highly individualistic phenomenon, the effects of which fade over a relatively short period of time". On the other hand, Karl (1972), after a careful review of the methodological issues in many studies concludes that the evidence does support the view that relocation causes deleterious effects on people with mental handicap. Similar conclusions have been drawn by others and one of the recent studies that outline guidelines for relocation suggests that this aspect should be considered carefully (Holtom *et al.*, 1990). However, extensive pre-relocation preparation can reduce the morbidity and mortality risks (Weinstock *et al.*, 1979).

Conclusion

This survey indicates that EPMH in a mental handicap hospital take up an increasing proportion of the total hospital population in comparison to that found by Spencer (1978), Ballinger (1978) and Day (1987) (TABLE VII). The EPMH

in this study have lower dependency rates and are more disturbed. About 33% of EPMH do not seem to require hospital care but should be prepared carefully to reduce the risks of relocation before they are resettled in the community. For those who remain in the hospital, construction of group homes and cottages within the grounds of the hospital, the hospital being situated well within the periphery of the local township, would enhance the quality of life for the remainder of their lives.

Summary

Fifty nine elderly people with mental handicap (EPMH), above the age of 65 years and living in a long stay mental handicap hospital in England, UK, were studied. 42.3% were functioning in the mild to moderate level of mental handicap range. 77.9% were under the age of 75 years and the female to male ratio was 1.56:1. Common geriatric problems such as cardio-respiratory (27.1%), alimentary (22%), hormonal (15.2%), nervous (10.1%) and genito-urinary (6.7%) diseases were found in this population. 30.5% had psychiatric disorders. Compared to the figures given by Day (1987), the population of EPMH in this study had less dependency needs but had more behaviour problems. It is suggested that their mental handicap needs are of far more importance than their geriatric needs. It is emphasized that the pre-relocation preparation, prior to their resettlement, should be carefully planned and instituted to reduce the morbidity and mortality associated with

relocation process. For those who remain in the hospital, suitable residential accommodation, within the hospital grounds, should be provided to enhance their quality of life, without undue delay.

Acknowledgements

The authors wish to thank the nurses of Stallington Hospital, Blythe Bridge who cheerfully cooperated with the study. Special thanks to Mrs. Katherine Roy and Miss Jannette Wiles, Librarians of Lea Castle Hospital, Kidderminster who obtained the references mentioned in the article.

Appendix A

PERSONAL CHARACTERISTICS

Age, sex, ethnic group, duration of stay and future placement.

Legal status, practical aids, day time activity and income.

Parents, siblings, family history of mental handicap and mental illness, visits from and to relatives and others.

Cause and degree of mental handicap, psychiatric disorders, chronic medical conditions, medications and epilepsy (frequency, severity and medication).

ITEMS IN DISABILITY ASSESSMENT

SCHEDULE (Holes *et al.*, 1982)

Mobility, continence (wetting/soiling-days/nights), self help (feeding, washing, dressing, toiletting), vision, hearing, communication (method, understanding, using and pronunciation), skills (reading, writing, counting and money, domestic, handicrafts), behavioural problems (physical aggression, destructive, overactive, attention seeking, self injury, wandering, screaming, temper tantrums, disturbances at night, objectionable behaviour, scatters objects, anti-social behaviours, unsocialised sexual activity), quality of social interaction, stereotypic behaviour (choice, simple, complex), echolalia (immediate, delayed, repetitive), and symbolism (imaginative, repetitive).

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