Mortality in relation to the functional capacities of people with disabilities living at home

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SUMMARY   The mortality experienced by a group of 1534 impaired people identified by means of a census-type survey of all households in the City of Canterbury is related to the degree of difficulty in carrying out selected self-care activities as reported by the impaired people. Although not entirely consistent, the findings in relation to people in their own homes agree with previously reported findings among patients in long-stay hospitals and residents in institutions that increasing difficulties in self-care (and therefore of dependency) are associated with increased mortality rates. These findings suggest that there is no clear boundary between some services for disabled people and those for terminal care, and that many severely handicapped people at home require co-ordinated and flexible care from nurses, social workers, and doctors.

Donaldson, *et al*[1] reported that among elderly residents in hospital or other institutions, mortality rates during one year were higher for people who had substantial difficulties in self-care than for people with moderate difficulties or none. We examined the hypothesis that similar findings would be obtained from a group of disabled people living at home. It seems obvious that frail and dependent people are more likely to die than those who can to a large degree still care for themselves. The importance of any positive association of disability and handicap with increased mortality would lie in the implications for the development and delivery of services. Furthermore, difficulty in self-care could be an alerting sign to doctors, nurses, social workers, and other carers, especially if the person is also aged 75 or over. Thus Wild *et al*[2] have recently reported that the main factor associated with increased mortality among a group of elderly people who had fallen at home was impaired mobility before the index fall, and Pathy and Peach[3] found that a low disability score was associated with a good prognosis both in terms of mortality and disability among elderly patients leaving hospital after a myocardial infarction.

Method

The surveys providing the data presented in this paper were designed to locate and describe people with impairments, disabilities, and handicaps living in private households within the boundaries of the City of Canterbury and to provide a baseline for a follow-up study of the impact of providing additional services. The results of these surveys have been reported elsewhere.[4 5] The definitions and survey methods used closely followed those developed by Harris in her national survey[6] and set out in her subsequent guidelines to social services departments of local authorities.[7] A one-page form containing 14 questions, asking if anyone in the household had one or other impairment or limitation in mobility or self-care, was delivered to every household in the city. There were 11 288 households with an estimated population of 33 145 people: however, 328 houses or flats were found to be unoccupied or had been demolished at the time of the survey so forms were delivered to the remaining 10 960 households. Usable replies were received from 10 159 (93%). This initial procedure identified 1608 people (5% of the population) as probably impaired, of whom 1534 (95%) subsequently had a screening interview.

The screening interview included 10 questions about self-care. The questions asked covered getting in and out of bed, using the lavatory, bathing, washing hands and face, putting on shoes, socks, or stockings, doing up buttons and zips, dressing, feeding, brushing hair (for women), and (for men) shaving. If the activity could be done without difficulty no score was allocated for that item; if the activity could be performed by the person but only

with difficulty then for seven items a score of 2 was given and a score of 4 for the remaining three items; and if the person needed the help of another person to carry out the activity then the scores were 3 for the seven items with the previously lower score and 6 for the other three items. The maximum score obtainable was 36 as two of the lower-scored items were alternatives for men and women. The items associated with the higher scores were using the lavatory, doing up buttons and zips, and feeding. The interviewers were trained and their returns checked. The items of activity were based on earlier work of Katz and his colleagues.[8]

Subsequent to this first household survey, a research assistant examined the records of the five statutory registers of handicapped people (in accordance with section 29 of the National Assistance Act, 1948) and of 15 agencies in Canterbury which were believed to be most likely to be in touch with people with disablement.[9] It was therefore possible to check how many registered handicapped people had been identified in the household survey, how many of the impaired people found through the household survey were already known to the services, and how many were being helped by them.

Two years after the first survey interviewers visited the households of all the people in the survey, except those households where it was known for certain that the person concerned had died. The interviewers were unaware of the data and self-care scores recorded in the first survey. Seven people in the original survey had not been traced when the follow-up survey was completed. It is known from subsequent information that at least five of them were alive at the time of the follow-up. The remaining two were aged 64 and 70, so even if these two had died these could not affect the main trend of the findings. Ninety-six people (6%) who did not wish to be interviewed again for the main follow-up study have been included in this report.

Results

Table 1 shows the age-distribution and distribution of self-care scores for the 1534 people with impairments who were identified and interviewed in the original survey. One-third (36%) were aged 75 or over and a further quarter (26%) were between 65 and 74. Most (58%) had no difficulties in self-care, but 181 (12%) had substantial difficulties in two or more items of activity. Major causes of the impairments were stated to be musculoskeletal diseases by 23% of the group, diseases of the central nervous system including strokes by 12%, circulatory disorders by 10%, respiratory disease by 5% and injuries by 4%. Other

Table 1 *Number of impaired people living at home and number of deaths within two years by age and self-care score groups*

Self-care scores*	All ages			Age groups (years) 0–34			35–64			65–74			75–84			85 or over		
	No impaired	Deaths	Death rate† per 1000	No impaired	Deaths	Death rate† per 1000	No impaired	Deaths	Death rate† per 1000	No impaired	Deaths	Death rate† per 1000	No impaired	Deaths	Death rate† per 1000	No impaired	Deaths	Death rate† per 1000
All scores	1534	206	134	157	0	—	420	28	67	399	60	150	416	76	183	142	42	296
0	885	81	91	102	0	—	280	11	39	235	27	115	203	27	133	65	16	246
1–4	288	48	167	15	0	—	52	7	135	75	12	160	116	22	190	30	7	233
5–11	180	38	211	8	0	—	42	4	—	52	12	231	51	12	235	27	10	370
12–26	131	23	176	17	0	—	35	2	—	30	6	200	35	9	257	14	6	429
27–36	50	16	320	15	0	—	11	4	—	7	3	—	11	6	545	6	3	—

*For scoring system see text.
†Death rates per 1000 people in the age/self-care score group over a period of about two and a quarter years. Rates for five or fewer deaths not shown.

causes were given by 18%. Some gave more than one disease as a cause, but a substantial number (mainly those with impairments of sight and hearing) gave no information about the cause for their impairment or disability.

Table 1 shows the number of deaths and the death rates per 1000 people for all ages and for each age group by self-care scores. Of the 1534 people in the study, 206 (91 men, 115 women) died between the first and second survey. Fifty-seven per cent were aged 75 or over, and 29% were between 65 and 74. No one under 35 died. On the whole, for each age group increasing self-care scores (and therefore of dependency) were associated with higher death rates. The exceptions could be due to random fluctuations or small numbers; if the highest two groups of scores are combined the trend is consistent.

As a result of the examination of the records of the various agencies helping people with disablement in Canterbury, it was found that one or more of the health, personal social or voluntary agencies were providing help to 51% of those people who died during the two years compared with 28% of the survivors. The home nurses and the home helps were particularly active in the care of those who died (table 2).

Discussion

As has already been stated, the data for this report have been taken from a study designed for other purposes, so it is necessary to consider their deficiencies in the present context. The follow-up survey extended for about six months, so that the period during which death might have occurred could be between two and two-and-a-half years for different individuals. As there was no allocation of people for follow-up interview by either age or self-care score, there is no reason to believe that a bias has been introduced.

As to the delivery of services three points can be made. Firstly, the findings of this study draw attention again to the heavy dependency of some people being cared for in the community.[10] Secondly, there is likely to be a high "turnover" of patients or clients needing maximum help due to their increased mortality rates. Thirdly, some of the services supplied by social services departments nominally for "disabled" people are in fact for people receiving terminal care; misunderstandings can arise from labelling groups of people as disabled or "terminal" (or whatever) and then attempting to direct a more-or-less fixed package of services to a supposedly homogeneous group. Heavily dependent people in the community are likely to require individual packages of services incorporating help from three or more services, often integrated with help from a spouse, relative, friend, or neighbour[11] and provided so that changing needs can be coped with.[5] Close collaboration between the general practitioner, the domiciliary nurse, and the personal social services is essential if problems arising from the disabilities and the concomitant medical conditions are to be relieved and the transition from efforts geared to maintaining independence to those providing terminal care[12] is to be achieved helpfully and at the appropriate time.

Table 2 *Recorded contacts with selected services of impaired people who died compared with those still alive at follow-up*

	Recorded by agency as in receipt of service			
	Those who died (n = 206)		Those still alive (n = 1328)	
Service	No	(%)	No	(%)
Home nurse	64	(31)	155	(12)
Home helper	49	(24)	137	(10)
Nursing aids	27	(13)	65	(5)
Day hospital	21	(10)	36	(3)
Meals-on-wheels	13	(6)	44	(3)
Laundry	3	(1·5)	7	(0·5)
On any one or more of records examined	105	(51)	366	(28)

References

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CORRECTION

Middlesbrough Meeting, September 1981 (June 1982, p 150)

The headline should read: "Summary of papers presented at meeting of the Society for Social Medicine in Middlesbrough. September 1981."

The following abstract of a paper given at this meeting has recently been received.

LOOKING AT CHANGES OVER TIME: GENERAL LESSONS FROM A STUDY OF THE HANDS OF PATIENTS WITH RHEUMATOID ARTHRITIS

The analysis of categorical data from longitudinal studies has been relatively neglected in statistical publications. In particular, ordinal scale data, because of its ordering, is often subjected to arbitrary scoring schemes or a dichotomisation is used to simplify the analysis.

Recently a class of models for ordinal regression was presented by McCullagh. For interpretation, these have the appeal that the observed response is governed by an underlying continuous variable. McCullagh deals only with situations where the responses for different values of the independent variable are not related. This is not the case for logitudinal data but Koch's general approach to categorical data using weighted least squares can be adapted to fit McCullagh's models.

This method has been used to analyse a study of the development of deformity in the hands of patients with rheumatoid arthritis. Together with Markov chain analysis, these approaches have shed light on whether the timing of early synovectomy is critical.

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