

The influence of patient and carer age in access to palliative care services

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Abstract

Background: older patients are less likely to receive palliative care than younger patients. As patient and primary carer age correlate positively, patterns may be due to carer rather than patient age, and reflect better ability to obtain support among younger carers.

Objective: to investigate how both patient and carer age relate to palliative care use, controlling for relevant variables.

Design: comparison of patients who received community Macmillan nurse specialist advice, Marie Curie nursing or inpatient hospice care with patients who did not, using univariate analysis and multivariate logistic regression. Patient and carer data were collected through electronic service record linkage and carer post-bereavement interviews.

Sample: patients referred to a hospice at home service whose primary carer could be interviewed ($n = 123$).

Results: whilst a cancer diagnosis was an important determinant of access for all services considered, logistic regression shows that carer age, but not patient age, and hospice at home access predicted Marie Curie nursing use. Both patient and carer age predicted use of Macmillan nurse advice. Age of the patient, but not carer age, predicted admission to inpatient hospice, alongside requiring care for over a month (all $P < 0.05$).

Conclusions: carer age may be as important a predictor of palliative home care use as patient age. We need to investigate whether younger carers have greater support needs or show greater effectiveness in obtaining help and to assess whether older carers need more assistance in recruitment of support.

Keywords: palliative, access, services, age factors, elderly

Introduction

Research has shown that older palliative cancer patients overall are less likely to receive palliative home care services [1–4] and inpatient palliative care [5,6] compared with younger patients.

Observed age differences in cancer treatment are not fully explained by clinical considerations such as co-morbidity or frailty [7, 8]. Observed age differences in end of life care are even more unlikely to be based on actual differences in need. Cartwright [9] concluded that those dying at 85 years or older have greater needs but less likelihood of receiving health care than younger patients. Gott *et al.* [10] found that

elderly hospitalised patients were more often identified as having palliative care needs than younger patients, yet less likely to be referred to palliative care beds. Evers *et al.* [11] argue that as patients over 80 are more likely to suffer dementia or stroke, standard palliative care is less equipped to address their needs. However, this is unlikely to explain age biases in palliative care access among cancer patients, as in the above studies.

Clinical judgements reportedly become more subjective and disparate as death approaches [12]. Both the difficulty in defining when patients are ready for palliative care [10, 13] and its holistic nature may make referral decisions more influenced by non-clinical factors. Patient age may be one

such variable. However, a further factor may be the role and characteristics of patients' carers, including carer age. As patient and carer age are positively correlated, the reported patient age bias in access to palliative care may in fact mask a carer age effect.

Logically, as patients approach death and become more psychologically and physically incapacitated, carers' influence on care recruitment will increase. Whilst the assessment of the patient by a health professional is paramount, carers often perform an important mediating role by seeking help, alerting professionals to problems or expressing dissatisfaction with care. When planning care, health professionals also consider the wider social context, including carers. Younger carers may be more distressed [14,15], dissatisfied with care [16, 17], more likely to adopt problem-focused coping [18] and to have other family and work commitments than older carers. If carer characteristics influence palliative care access, these would often be age related.

The present study investigates the relationship between patient and carer age and use of Macmillan specialist advice, Marie Curie home nursing and inpatient hospice care. The study utilises data from patients referred to hospice at home (HAH) during a randomised controlled trial (RCT) during which both carer characteristics and the use of palliative care services in the last year of life were recorded [19].

The analysis controls for carer age-related variables, including the generational relationship with the patient, whether the patient lived alone, and carer commitments such as young children or impact of caring on employment. Also considered are variables known to be associated with palliative care access, including patient sex [20], socio-economic status (SES) [2, 3], cancer versus non-cancer diagnosis [21], type of cancer [2, 5], length of care period [1], as well as carer sex, as genders may differ in their effectiveness as carers [22] or respond differently to caring [15]. Finally, potential effects of HAH referral and RCT allocation on service access are considered.

Methods

Sample

The sample comprised patients referred to HAH during an RCT [19], whose key carer could be identified from referral records, contacted by letter 6 months post-bereavement, and who agreed to participate in an interview. Patients were randomised to HAH and standard care or standard care only at a ratio of 4:1, but 8% of patients were not randomised due to referral fluctuations or 'emergency' referrals [19]. The current analysis includes both cases that entered the RCT and those who did not. HAH provided up to 24 h nursing care at home for ~2 weeks. HAH was mainly for adult patients of all diagnoses for whom death was anticipated within 2 weeks, although some respite care could be provided for patients with cancer, motor neurone disease or acquired immune deficiency syndrome (AIDS). The HAH catchment area was the

former Cambridge Health District in the UK. All patients had a general practitioner and all but three received district nursing care.

Standard care included Macmillan nurses, palliative care clinical nurse specialists who work with patients and professionals to address symptom control and psychosocial needs; Marie Curie nursing which involves experienced, extended, hands-on palliative care in the home; and inpatient hospice care with access to palliative care specialists.

Data collection

Patient age and sex, postcode, RCT status, whether living alone, diagnosis and key carer's sex and relationship with the patient were obtained from HAH records. Diagnosis was cross-checked with data from the Office of National Statistics (ONS) and East Anglian Cancer Intelligence Unit. Jarman Underprivileged Area (UPA) scores [23] for ward of residence were derived from the patient's postcode.

Carer age, length of care dependency as reported by the carer, impact of caring on employment, and age of the carer's children were collected from carer interviews.

Patient occupation was obtained from ONS and the Cambridge and Huntingdon Health Authority and allocated to SOC Occupational Unit Groups [24]. Patients' social class was subsequently derived from these codes.

Macmillan and inpatient hospice input were obtained from local NHS Community Trust databases, and Marie Curie input from a service database designed for the research [4]. Service input was cross-checked with carers during interview.

Analysis

Table 1 lists all the variables tested in the univariate analysis. Differences between patients who received a palliative care service and those who did not were analysed using *t*-tests for continuous variables. For categorical variables, χ^2 tests with Yates's continuity correction or Pearson's χ^2 tests were used as appropriate [25]. All tests were two-tailed.

To assess whether access to HAH may influence access to other services, we considered whether those unable to access HAH due to the RCT trial were less or more likely to access other services. We also considered whether these services' start date, as recorded on service databases, occurred before or after referral to HAH, as recorded in HAH records.

Multivariate forward stepwise logistic regression analyses were performed to assess the relative contributions of patient and carer age to service access, controlling for other variables. Variables that differed between service recipients and non-recipients at $P < 0.25$ entered the multivariate analysis, as recommended by Hosmer and Lemeshow [26], because variables may contribute to the model in unforeseen ways due to complex inter-relationships. Categorical variables were entered into analysis using the categories shown in Table 1.

Separate analyses were conducted for each service (Marie Curie, inpatient hospice and Macmillan care) to

Table 1. Demographic and clinical variables by service input: Marie Curie care, inpatient hospice care and Macmillan care ($n = 123$ for Marie Curie and hospice care, $n = 98$ for Macmillan care, unless otherwise stated)

	Marie Curie care		Inpatient hospice care		Macmillan care	
	Yes	No	Yes	No	Yes	No
Patient age [mean (SD)]	69.3 (15.0)*	75.1 (12.6)	68.1 (14.4)*	74.3 (13.7)	63.4 (12.0)***	76.4 (10.0)
Patient gender [n (%)]						
Male	29 (44%)	31 (54%)	21 (46%)	39 (51%)	21 (51%)	26 (46%)
Female	37 (56%)	26 (46%)	25 (54%)	38 (49%)	20 (49%)	31 (54%)
Patient living alone [n (%)]						
Yes	10 (15%)	7 (13%)	7 (15%)	10 (13%)	6 (15%)	9 (16%)
No	56 (85%)	49 (88%)	39 (85%)	66 (87%)	35 (85%)	48 (84%)
Jarman deprivation index ^a [mean (SD)]	1.45 (14.89)	0.37 (16.28)	1.25 (15.55)	0.77 (15.55)	3.92 (14.67) ⁺	-1.94 (14.94)
Occupational class [n (%)]	($n = 118$)		($n = 118$)		($n = 94$)	
I	9 (14%)	6 (11%)	3 (7%)	12 (16%)	2 (5%)*	10 (19%)
II	14 (22%)	20 (36%)	14 (32%)	20 (27%)	11 (28%)	17 (32%)
IIIN	10 (16%)	4 (7%)	7 (16%)	7 (10%)	4 (10%)	8 (15%)
IIIM	15 (24%)	11 (20%)	9 (21%)	17 (23%)	14 (35%)	6 (11%)
IV-V	15 (24%)	14 (26%)	11 (25%)	18 (24%)	9 (23%)	13 (24%)
Cancer versus non-cancer [n (%)]						
Cancer	59 (89%)**	39 (68%)	44 (96%)**	54 (70%)	N/A	N/A
Non-cancer	7 (11%)	18 (32%)	2 (4%)	23 (30%)	N/A	N/A
Diagnosis (cancer) [n (%)]	($n = 95$)		($n = 95$)		($n = 95$)	
Breast	8 (14%)	3 (8%)	6 (14%)	5 (9%)	5 (13%)	6 (11%)
Gastrointestinal	10 (18%)	9 (24%)	7 (17%)	12 (23%)	9 (23%)	10 (18%)
Genitourinary	14 (25%)	13 (34%)	15 (36%)	12 (23%)	10 (26%)	17 (30%)
Lung	7 (12%)	4 (11%)	3 (7%)	8 (15%)	4 (10%)	7 (13%)
Other	18 (32%)	9 (24%)	11 (26%)	16 (30%)	11 (28%)	16 (29%)
Length of care dependency ^b [n (%)]	($n = 122$)		($n = 122$)		($n = 97$)	
<1 month before death	12 (18%)	11 (20%)	4 (9%)+	19 (25%)	8 (20%)	14 (25%)
1-3 months	19 (29%)	18 (32%)	12 (27%)	25 (33%)	15 (38%)	17 (30%)
3-6 months	10 (15%)	13 (23%)	12 (27%)	11 (14%)	6 (15%)	12 (21%)
6-12 months	14 (21%)	5 (9%)	10 (22%)	9 (12%)	7 (18%)	8 (14%)
≥1 year	11 (17%)	9 (16%)	7 (16%)	13 (17%)	4 (10%)	6 (11%)
RCT status [n (%)]						
Control	7 (11%)+	14 (25%)	5 (11%)+	16 (21%)	10 (24%)+	7 (12%)
Not control	59 (89%)	43 (75%)	41 (89%)	61 (79%)	31 (76%)	50 (88%)
Carer age [mean (SD)]	($n = 120$)		($n = 120$)		($n = 95$)	
	58.6 (12.2)*	63.9 (12.5)	58.9 (11.8) ⁺	62.4 (12.9)	55.2 (10.3)***	65.3 (12.4)
Carer gender [n (%)]						
Male	25 (38%)	19 (33%)	18 (39%)	26 (34%)	20 (49%)+	18 (32%)
Female	41 (62%)	38 (67%)	28 (61%)	51 (66%)	21 (51%)	39 (68%)
Carer generation [n (%)]						
Same as patient	42 (64%)	40 (70%)	33 (72%)	49 (64%)	30 (73%)	39 (68%)
Different from patient	24 (36%)	17 (30%)	13 (28%)	28 (36%)	11 (27%)	18 (32%)
Carer dependants under 18 years [n (%)]						
Yes	6 (13%)	7 (9%)	8 (12%)	5 (9%)	6 (15%)+	3 (5%)
No	40 (87%)	70 (91%)	58 (88%)	52 (91%)	35 (85%)	54 (95%)
Carer employment change [n (%)]						
None	39 (60%)	37 (69%)	30 (67%)	46 (62%)	21 (51%)*	42 (78%)
Reduced or stopped work	26 (40%)	17 (32%)	15 (33%)	28 (38%)	20 (49%)	12 (22%)

⁺ $P < 0.25$; * $P < 0.05$; ** $P < 0.01$; *** $P < 0.001$.^a Higher score represents higher deprivation.^b As reported by carer.

investigate which variables best predicted which patients were likely to be a user or non-user of each. Analyses for Marie Curie and inpatient hospice included the whole sample. The Macmillan analysis was limited to cancer patients only, as only cancer patients received Macmillan input. Here the inclusion of non-cancer patients would yield a contingency table with a zero cell, which should be avoided in logistic regression [26]. However, cancer diagnosis clearly is important in Macmillan care access. SPSS 12.0 was used for statistical analysis.

Results

Sample

During the study, 249 patients were referred to HAH and subsequently died. A key informal carer could be identified for 214 (86%) and contacted post-bereavement. Of these, 123 (57%) agreed to participate in an interview. They represented 94 patients randomised to HAH, 21

controls and eight who were not randomised and had the same access to HAH as intervention patients. Patients of carers who participated in the study were less likely to have lived alone than patients of non-participants, but otherwise did not differ from non-participants in terms of age, sex, diagnosis (cancer/non-cancer) or service use.

Forty-six (37%) carers were wives of the patient, 33 (27%) husbands, 24 (20%) daughters, nine (7%) sons and 11 (9%) other. Mean patient age was 71.9 (SD 14.2) years and mean carer age 61.1 (SD 12.6) years (see Table 1 for further details).

Service use

Table 1 shows the number of patients receiving each service. Thirty-five of 46 began their inpatient hospice care, 36 of 41 their Macmillan nursing, and 46 of 66 their Marie Curie nursing before referral to HAH. Thus, if HAH RCT status influenced access to these services, it would only have done so for a minority of patients. Overall, 34 (28%) patients had neither Marie Curie, Macmillan nor hospice input (16 of these were non-cancer). Forty-three (35%) had one service, 28 (23%) had two and 18 (15%) had all three.

Variables associated with access

Compared with those who did not receive care, patients who received Marie Curie and Macmillan nursing were both younger and had younger carers than their counterparts, while patients who received hospice care were younger ($P < 0.05$, Table 1). Patients who had Marie Curie and hospice

care were significantly more likely to have cancer than their counterparts (and Macmillan care was exclusive to cancer patients). Finally, Macmillan care recipients were more likely to be in lower rather than higher occupational classes, and their carers more likely to have had to reduce or stop work.

Based on the lax criterion of $P < 0.25$, the variables entering multivariate logistic regression analysis for Marie Curie care were patient and carer age, cancer versus non-cancer diagnosis and RCT status. Variables entering analysis for hospice care were patient and carer age, cancer versus non-cancer diagnosis, length of care dependency and RCT status. Variables entering analysis for Macmillan care were patient and carer age, carer gender, carer employment change, carer dependants under 18 years, patient occupational class, Jarman deprivation index and RCT status. Table 2 shows the resulting logistic regression models. For categorical data, the last category is the reference category. The probability level for entry into the models was set to $P < 0.05$.

The model for Marie Curie care shows that having cancer is the greatest determinant of service use [odds ratio (OR) = 4.25]. Carer age was furthermore negatively associated with Marie Curie nursing, i.e. the likelihood of obtaining the service decreased with age (OR = 0.96). Once carer age was accounted for, patient age made no significant additional contribution. Access to HAH was also significantly positively associated with Marie Curie nursing (OR = 2.88).

For inpatient hospice care, having cancer was again the clearest predictor of service use (OR = 18.90). Patient age was negatively associated with inpatient hospice access (OR = 0.97), but carer age did not contribute to the model. The length of care dependency was an additional significant predictor of hos-

Table 2. Variables associated with access to palliative care services: forward stepwise multivariate logistic regression analyses

	Coefficient (SE)	Odds ratio (95% CI)	Significance
Marie Curie ($n = 120$)^a			
Carer age	-0.037 (0.017)	0.964 (0.934–0.996)	$P = 0.0263$
Cancer diagnosis			
Cancer	1.448 (0.513)	4.253 (1.556–11.626)	$P = 0.0048$
Non-cancer	0	1	
HAH RCT status			
Access to HAH	1.059 (0.526)	2.882 (1.028–8.081)	$P = 0.0442$
Control	0	1	
Inpatient hospice ($n = 119$)^b			
Patient age	-0.035 (0.016)	0.966 (0.935–0.997)	$P = 0.0326$
Cancer diagnosis			
Cancer	2.939 (0.859)	18.900 (3.513–101.689)	$P < 0.0006$
Non-cancer	0	1	
Length of care dependency			
Less than a month	-1.987 (0.841)	0.137 (0.026–0.712)	$P = 0.0181$
1–3 months	-1.198 (0.728)	0.302 (0.073–1.258)	$P = 0.1000$
3–6 months	-0.019 (0.763)	0.981 (0.220–4.375)	$P = 0.9798$
6–12 months	0.222 (0.806)	1.248 (0.257–6.055)	$P = 0.7831$
≥ 1 year	0	1	
Macmillan ($n = 89$)^c			
Patient age	-0.104 (0.027)	0.901 (0.855–0.950)	$P = 0.0001$
Carer age	-0.068 (0.025)	0.934 (0.890–0.980)	$P = 0.0056$

^aCases predicted correctly: 69.2%; model $\chi^2 = 18.20$, $df = 3$, $P = 0.0004$

^bCases predicted correctly: 75.6%; model $\chi^2 = 32.98$, $df = 6$, $P < 0.0001$.

^cCases predicted correctly: 76.4%; model $\chi^2 = 34.83$, $df = 2$, $P < 0.0001$

pice access in the model. Patients who required help physically for <1 month were significantly less likely to receive hospice care compared with those who required care for a year or more.

The model for Macmillan nursing shows that both patient (OR = 0.90) and carer (OR = 0.93) age were independently negatively associated with service use. No other variable reached significance in the model, but we should note that only cancer patients received Macmillan care and entered this analysis.

Discussion

Summary

Whilst cancer is a major determinant of access to palliative care, both older patient age and older carer age were associated with worse access to palliative care. Carer age appeared more important for care delivered in the home, i.e. Marie Curie and Macmillan nursing. Patients who had Marie Curie and Macmillan nursing were both younger and had younger carers than those who did not in the univariate analysis. In the multivariate analysis, carer age, but not patient age, predicted Marie Curie use, whilst both patient and carer age predicted Macmillan use. In contrast, inpatient hospice admission was negatively related only to patient age. The results confirm previous findings that patient age is negatively associated with palliative care access, both home and inpatient care [1–6], but show an added and independent contribution of carer age for home care.

The results furthermore confirmed that cancer diagnosis is strongly linked with palliative care access for all three services investigated [21]. Cancer remained a strong independent predictor of Marie Curie and inpatient hospice use in the multivariate analysis, and only cancer patients received Macmillan care.

In contrast to previous research on SES, lower occupational groups appeared more likely to have Macmillan nursing [2, 3], but this relationship disappeared in the multivariate analysis. Carers of Macmillan patients were more likely to have had their employment affected by caring. However, this may simply reflect carer age, as younger carers were more likely to be employed, and the variable was no longer significant when multivariate analysis controlled for carer age. Patients who required care for <1 month were significantly less likely to receive inpatient hospice care, which may reflect that a short care period often can be sustained at home. Multivariate analysis showed that patients who had access to HAH were also more likely to receive Marie Curie care. HAH access may therefore in some cases have facilitated Marie Curie care, as HAH and Marie Curie care were under the same home care management.

Weaknesses

A weakness of the study is that the sample comprised patients referred to HAH. The majority of referrals are cancer patients (87%) and represent 25% of cancer deaths locally. Patients referred to HAH are younger, live in less deprived areas, are less likely to be diagnosed within a month of death and to have causes other than cancer recorded on their death certificate, and are more likely to have

palliative care input than the palliative population as a whole [4]. Only 57% of carers agreed to participate in the study, although this represents a good response rate within palliative care studies, and patients of participating carers were less likely to have lived alone than patients of non-participants. The patterns observed may therefore not be generalisable to all. Nevertheless, within this sample, we observed the same negative relationship between patient age and palliative care access reported in past studies [2–6]. If the patient age patterns reflect a robust, general pattern, it is plausible that the carer age patterns also do so. In fact, if these age patterns remain in a relatively homogenous sample, they may be even clearer within the general palliative care population.

We should interpret the multivariate logistic regression results with care. For instance, although patient age failed to reach statistical significance for Marie Curie care, this may not mean that it makes no contribution, only that carer age emerged as a stronger predictor for this particular sample.

Finally, we were not able to assess how age was related to carer and patient context, except in a very superficial way, such as number of children under age 18 and change in employment. The caregiving context of different age groups rather than age *per se* may be the important factors in palliative care access. An understanding of context and whether age differences relate to cohort differences or differences in life trajectory is required to explain the patterns fully and identify solutions.

Carer age and palliative care access

Once patient age is controlled for, carer age differences in palliative care access should not be related to any potential patient age differences in need. Carer age appeared to be more important in relation to home care. Given the importance of the primary carer for home care and home death [22], it is plausible that carer context and considerations are more prominent for home care than inpatient care. Younger carers may have greater need for resource input than older carers. Alternatively, younger age may be associated with greater effectiveness in obtaining care.

Younger carers may be more likely to be in paid work, responsible for young children and to run a separate household from that of the patient if of a younger generation. Based on life situation, health professionals may therefore assess their support needs as greater than those of older people living together. The same life factors may motivate younger carers to seek additional help, and they may also psychologically be in greater need of support [14, 15, 27, 28, 29]. Nevertheless, older carers are more likely to suffer age-related disability and ill health. The requirement for assistance with physically demanding aspects of caregiving should therefore increase with age.

An alternative explanation to a carer age bias in access to palliative care may be that younger carers are more effective at obtaining care. Younger age may be associated with greater dissatisfaction with care, which may result in greater motivation to improve support [16,17]. Younger carers also reportedly adopt more problem-focused coping than older carers, i.e. investing active effort in solving problems [18]. Conversely, older age has in general been linked to less

problem-focused coping and more resigned acceptance [30]. Therefore, to the extent that carers do recruit help and act as patients' advocates, younger carers may be more proactive and demanding *vis a vis* the support services than older carers. Younger carers may also be better able to establish rapport with health professionals through greater similarities in age, life situation and education.

The present study shows carer age differences in access to palliative care that warrant further investigation, as conflicting explanations have very different implications for future action. If carer age differences are based on genuine age differences in need, we need to identify how carers' requirements differ with age and target services accordingly. If differences reflect younger carers' greater effectiveness in recruiting help and having their concerns recognised by health professionals, we need to consider how to empower older carers and help health professionals recognise their needs.

Key points

- Older patient age is associated with poorer access to palliative care. This may mask age differences in access due to carer age
- This study found that carer age was at least as important as patient age in predicting access to palliative home care
- If carer age differences reflect that younger carers' have greater need for support, health professionals may need to become more responsive to the support requirements of younger carers.
- If carer age differences reflect younger carers' greater effectiveness in recruiting care, there is a need to ensure that older carers' home care requirements are better heard and responded to by health professionals.

Acknowledgements

We wish to thank the carers who contributed to this study, the Cambridge Hospital at Home for palliative care, and Dr Malcolm Campbell for statistical advice. The project was approved by the Cambridge Local Research Ethics Committee and informed consent obtained from respondents.

Conflict of interest

None.

Funding

The research was funded by the NHS Executive Eastern grant RCC33030 and Directorate of Health and Social Care Midlands and East of England Grant RCC11095. The financial sponsors played no role in the design, execution, analysis, interpretation or writing of the study.

References

1. McCusker J. The use of home care in terminal care. *Am J Prev Med* 1985; 1: 42–52.
2. Costantini M, Camoirano E, Madeddu L, Bruzzi P, Verganelli E, Henriquet F. Palliative home care and place of death among cancer patients: a population-based study. *Palliative Med* 1993; 7: 323–31.
3. Addington-Hall J, Altmann D. Which terminally ill cancer patients in the United Kingdom receive care from community specialist palliative care nurses? *J Adv Nurs* 2000 32: 799–806.
4. Grande GE, McKerral A, Todd CJ. Which cancer patients are referred to Hospital at Home for palliative care? *Palliative Med* 2002; 16: 115–23.
5. Owen T, ed. *Dying in Older Age: Reflections and Experiences From an Older Person's Perspective*. London: Help the Aged, 2005.
6. Addington-Hall JM, Altmann D, McCarthy M. Which terminally ill cancer patients receive hospice in-patient care? *Soc Sci Med* 1998; 46: 1011–6.
7. Turner NJ, Haward RA, Mulley GP, Selby PJ. Cancer in old age—is it inadequately investigated and treated? *Br Med J* 1999; 319: 309–12.
8. Bailey C, Corner J, Addington-Hall J, Kumar D, Nelson M, Haviland J. Treatment decisions in older patients with colorectal cancer: the role of age and multidimensional function. *Eur J Cancer Care* 2003; 12: 257–62.
9. Cartwright A. Dying when you're old. *Age and Ageing* 1993; 22: 425–30.
10. Gott MC, Ahmedzai SH, Wood C. How many inpatients at an acute hospital have palliative care needs? Comparing the perspectives of medical and nursing staff. *Palliative Med* 2001; 15: 451–60.
11. Evers MM, Meier DE, Morrison RS. Assessing differences in care needs and service utilization in geriatric palliative care patients. *J Pain Sympt Manage* 2002; 23: 424–32.
12. Maher EJ, Jefferis AF. Decision making in advanced cancer of the head and neck: variation in the views of medical specialists. *J R Soc Med* 1990; 83: 356–9.
13. Farquhar M, Grande G, Todd C, Martin A, Barclay S. Defining patients as palliative: hospital doctors' versus General Practitioners' perceptions. *Palliative Med* 2002; 16: 247–50.
14. Higginson IJ, Priest P. Predictors of family anxiety in the weeks before bereavement. *Soc Sci Med* 1996; 43: 1621–5.
15. Payne S, Smith P, Dean S. Identifying the concerns of informal carers in palliative care. *Palliative Med* 1999; 13: 37–44.
16. Maflulll YM, Morriss RK. Determinants of satisfaction with care and emotional distress among informal carers of demented and non-demented elderly patients. *Int J Geriatr Psychiatry* 2000; 15: 594–9.
17. Shilling V, Jenkins V, Fallowfield L. Factors affecting patient and clinician satisfaction with the clinical consultation: can communication skills training for clinicians improve satisfaction? *Psycho-oncology* 2003; 12: 599–611.
18. Harding R, Higginson IJ, Donaldson N. The relationship between patient characteristics and carer psychological status in home palliative cancer care. *Support Care Cancer* 2003; 11: 638–43.
19. Grande GE, Todd CJ, Barclay SIG, Farquhar MC. A randomised controlled trial of a hospital at home service for the terminally ill. *Palliative Med* 2000; 14: 375–85.
20. McCusker J, Stoddard AM. Effects of an expanding home care program for the terminally ill. *Med Care* 1987; 25: 373–85.
21. Addington-Hall J. *Reaching Out: Specialist Palliative Care for Adult with Non-malignant Diseases*. National Council for Hospice and Specialist Palliative Care Services and Scottish Partnership Agency for Palliative and Cancer Care, Occasional Paper 14, 1998.
22. Grande GE, Addington-Hall JM, Todd CJ. Place of death and access to home care services: are certain patient groups at a disadvantage? *Soc Sci Med* 1998; 47: 565–79.

23. Jarman B. Identification of underprivileged areas. *Br Med J* 1983; 286: 1705–08.
24. Office of Population Censuses and Surveys. Standard Occupational Classification: Volume 2. Coding Index. London: HSMO, 1990.
25. Siegel S, Castellan NJ. Nonparametric Statistics for the Behavioural Sciences, 2nd edn. Singapore: McGraw-Hill, 1988.
26. Hosmer DH, Lemeshow S. Applied Logistic Regression, 2nd edn. New York: Wiley, 2000.
27. Clipp EC, George LK. Dementia and cancer: a comparison of spouse caregivers. *Gerontologist* 1993; 33: 534–41.
28. Meyers JL, Gray LN. The relationships between family primary caregiver characteristics and satisfaction with hospice care, quality of life and burden. *Oncol Nurs Forum* 2001; 28: 73–82.
29. Chan CWH, Chang AM. Experience of palliative home care according to caregivers' and patients' ages in Hong Kong Chinese people. *Oncol Nurs Forum* 2001; 27: 1601–5.
30. Folkman S, Lazarus RS, Pimley S, Novacek J. Age differences in stress and coping processes. *Psychol Ageing* 1987; 2: 171–84.

Received 16 June 2005; accepted in revised form 2 February 2006

Age and Ageing 2006; 35: 273–279
doi:10.1093/ageing/afj074

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Relationships between long-term stroke disability, handicap and health-related quality of life

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Abstract

Objectives: to estimate levels of disability, handicap and health-related quality of life (HRQOL) up to 3 years after stroke and examine the relationships between these domains.

Design: a longitudinal, observational study

Setting: population-based register of first-ever strokes

Methods: subjects, registered between 1 January 1995 and 31 December 1997, were assessed at 1 year ($n = 490$) and 3 years ($n = 342$) post-stroke for disability [Barthel index (BI)], handicap [Frenchay activity index (FAI)] and HRQOL (SF-36). BI was categorised as severe, moderate, mild and independent (0–9, 10–14, 15–19 and 20); FAI was categorised as inactive, moderately active and very active (0–15, 16–30 and 31–45). SF-36 domains include: Physical Functioning (PF), Role Physical (RP), Bodily Pain (BP), General Health (GH), Vitality (VT), Social Functioning (SF), Role Emotional (RE) and Mental Health (MH). Physical (PHSS) and Mental Health (MHSS) Summary Scores were computed.

Results: at 1 and 3 years, 26.1 and 26.3%, respectively, were disabled (BI <15); 55 and 51%, respectively, were handicapped (FAI = 0–15); and survivors had low mean PHSS (37.1 and 37.9), but satisfactory mean MHSS (46.6 and 47.7). There was a graded positive relationship between all SF-36 domains and the categories of BI and FAI. Spearman rank correlations were significant between BI and all SF-36 domains at both time points: strong ($r > 0.70$) with PF, moderate ($r = 0.31–0.70$) with RP, SF and PHSS, but weak ($r < 0.30$) with other domains. Correlations between FAI and SF-36 domains were strong with PF, weak with BP, RE and MHSS, and moderate with other domains.

Conclusions: disability and handicap remain highly prevalent up to 3 years after stroke. Patients' perception of physical health is persistently low, but mental health perception is satisfactory up to 3 years. Due to variable correlations between different HRQOL domains with disability and handicap, it is suggested that disability, handicap and HRQOL should all be assessed to acquire a broader measure of stroke outcome.

Keywords: stroke, long-term outcomes, disability, handicap, quality of life, elderly