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Views of elderly people on living wills: interview study

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Living wills or advance statements record people's healthcare wishes in case they are unable to contribute to a decision concerning their health care in the future, either because of mental incapacity or because physical disability prevents communication.[1] Elderly people are often in this position owing to illnesses such as dementia and strokes that cause dysphasia. The views of elderly North Americans on this subject are well documented, but there are no reports of the views of older people in England.[2 3] This study aimed to determine the knowledge of elderly inpatients in the United Kingdom on living wills and their healthcare choices should they write such a will.

Participants, methods, and results

Seventy four out of 76 medical inpatients approached answered a questionnaire administered by one interviewer (RS) at two hospitals in London. All participants were aged over 65 and had a normal score on the abbreviated mental test. Ethical approval had been obtained.

The participants' mean age was 81 (range 66-97) years; 73 participants were white and one was Asian (lack of fluency in English precluded other eligible people). Most lived in independent housing (69; 93%), either alone (44; 64%) or with family members (25; 36%). One participant was wheelchair dependent; others could walk: 25 (34%) independently, 26 (35%) with sticks, 22 (30%) with a frame. Half received home help. Of 69 participants who completed the BASDEC depression profile, 11 had a score of 7 or above,[4] suggesting depression.

Sixty one participants (82%; 95% confidence interval 72% to 90%) had not heard of living wills, advance directives, or advance statements. Of the 13 people who said they had heard of living wills, only four correctly defined them; most, as previously noted,[3] thought that the term applied to financial arrangements after death.

Most people chose relatives as a healthcare proxy:12 (17%; 9% to 27%) chose their spouse and 45 (63%; 50% to 73%) chose other relatives; friends (n = 4 (6%; 2% to 13%) and doctors (n = 16 (22%; 13% to 34%) were also nominated. People were specific as to which family member they would wish consulted. Five of 17 people living with their spouse (29%; 10% to 56%) did not choose them as a healthcare proxy. They stated it was not fair to expect them to make these types of decisions; they would be too emotional to be rational and they would not make the decision the participant would have wanted. Seventeen (24%; 14% to 35%) had discussed issues surrounding medical care with their proposed healthcare proxies.

Our elderly participants found many disabilities unacceptable, stating that they preferred "comfort only" care, even if they might die, to active treatment (table). The single condition most feared was advanced dementia (n = 56 (78%; 66% to 87%), and this became even less acceptable when combined with other disabilities. Least feared was being in a wheelchair (n = 17 (24%; 14% to 35%). Women were less likely than men to request active treatment options: geometric mean (out of 27 disabilities) 3.2 for women, 6.5 for men; ratio difference = 2.0 (1.1 to 3.8; P = 0.04) after adjustment for age.

Percentage of patients (n=74) who would not want active treatments for any additional illness (for example, pneumonia) if they had disabilities. The diagonal gives the percentage of participants preferring "comfort only" care should they have one of seven disabilities and the other results refer to a combination of two of them

Disability	Unable to speak	In a wheelchair	Bed bound	Fed by percutaneous endoscopic gastrostomy	Advanced dementia	Blind	Doubly incontinent
Unable to speak	52						
In a wheelchair	64	24					
Bed bound	78	NA	58				
Fed by percutaneous endoscopic gastrostomy	77	74	81	57			
Advanced dementia	90	83	92	90	78		
Blind	82	78	82	79	88	44	
Doubly incontinent	82	76	81	79	89	82	53

NA=not applicable.

At the end stage of a terminal disease, 68 people (94%) said they would refuse surgery, 67 (93%) artificial feeding, 66 (92%) ventilation, 65 (90%) cardiopulmonary resuscitation, 62 (86%) subcutaneous or intravenous fluids, and 59 (82%) antibiotics.

Fifty participants (74%) expressed interest in writing a living will, most commonly because their views would be known (25; 34%) and to relieve the burden of decisions on their family (22; 30%). Women and men were equally interested in writing a living will.

Comment

Despite little previous knowledge of living wills, many older people were interested in the concept. Most elderly people have clear views on the issues raised in living wills, and 92% indicated when they would no longer wish their lives to be prolonged by medical interventions. A living will specially designed for elderly people may be appropriate and is being prepared.

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Contributors: RS had the original idea for the study and will act as guarantor; RS, CB and CR designed the questionnaire; RS conducted the interviews. RS wrote the first draft of the paper, CB and CR revised the manuscript.

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Correction

Burns after photodynamic therapy

An authors' error occurred in this drug point by Shehan Hettiaratchy and others (6 May, p 1245). The last sentence of the second paragraph should have read, "All subjects signed a standard consent form of the Association of the British Pharmaceutical Industry and no fault compensation is available" rather than the published, "As the men had signed disclaimers before the trial, they were not automatically entitled to compensation."

Family medicine

Two case histories

My mother in law has never been a great walker, but at nearly 80 she has kept active and takes a lively interest in the world and her family. She and her husband love Majorca and spend time there every winter. She has put on some weight over the years and her knees began to cause trouble. Just before Christmas they got worse and her break in Majorca was partly spoilt by a stiff neck. On her return she was treated to a massage, but she was finding it difficult to walk up stairs and wondered if she would need knee replacements. I realised all was not well when she had to do the weekly ironing session sitting down. Also, for the first time in the 30 years that I have known her, she had lost her joie de vivre. Never a complainer, she visited my partner three months after her symptoms had started. An erythrocyte sedimentation rate of 91, haemoglobin of 10.9, and normal protein electrophoresis made the diagnosis obvious. Within 24 hours of oral steroids her bounce had returned.

My mother has been a keen walker all her life and never puts on weight. She joined a prestigious fell walking club in her 80th year, and at 81 she went to Scotland to "bag some Munros" (Scottish mountains over 3000 feet). In March during a walk near her London home she developed severe cramp in her hips and after leaving the lunchtime pub had to give up. The acute pain settled, but walking became more difficult. Her GP referred her for a hip replacement, and we worried about her future mobility. When we visited in April I was shocked to see her limping. The next weekend she visited us and complained that she had strained her shoulder in the garden. When I rang the following week she was finding it hard to climb the stairs and could not turn over in bed. The penny dropped with a clang. Never one to complain, she hadn't told her GP of all these symptoms. A few days later the erythrocyte sedimentation rate came back at 65 and the haemoglobin at10.2. The hip radiograph was within normal limits. While awaiting the results she became almost immobile and didn't know how she could carry on. Within two hours of taking the steroids she could get out of the chair without difficulty, and that night she could sleep again, although full mobility took several weeks to return.

Diagnosed with polymyalgia rheumatica within two weeks of each other, they swap steroid stories and compare doses. Both sides of the family went to Majorca this October to celebrate the 80th birthday. Some walked further than others, but all had a spring in their step.

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