

A comprehensive health care directive in a home for the aged

D. William Molloy, MB; Gordon H. Guyatt, MD

Objectives: To examine the use of and compliance with a new comprehensive health care directive by residents of a home for the aged and to determine the effect of the directive on the use of health care services.

Design: Descriptive study with a before-after design.

Setting: A home for the aged providing residential care to women.

Participants: All 119 residents (ages 71 to 103 years, mean age 87.5 years).

Intervention: Introduction of a comprehensive health care directive and follow-up at 1 year.

Outcome measures: Residents' treatment choices, compliance with the directive, number of hospital admissions and length of hospital stay, number of deaths and places where deaths occurred.

Results: Ninety (76%) of the residents completed the directive. In the event of reversible life-threatening illness 34, 24, 11 and 21 residents requested supportive, limited, maximum and intensive care respectively. For irreversible illness the numbers were 75, 12, 3 and 0 respectively. In case of cardiac arrest 88% requested that cardiopulmonary resuscitation not be done. In the year before the introduction of the directive there were nine deaths, one in the home and eight in hospitals. In the year after there were 17 deaths, 11 in the home and 6 in hospitals. The mean length of hospital stay was significantly lower in that year than in the year before implementation ($p < 0.001$).

Conclusions: This innovative health care directive seems to be feasible, practical and well supported by residents, their families and health care professionals. Further studies are required to establish the generalizability and reproducibility of the data to other elderly people in institutions, to chronically ill patients and to the community at large.

Objectifs : Examiner l'utilisation et le respect d'une nouvelle directive de soins complets de santé par les résidentes d'un centre d'accueil pour personnes âgées et déterminer l'effet de la directive sur l'utilisation des services de santé.

Conception : Étude descriptive avec plan avant-après.

Contexte : Un centre d'accueil pour personnes âgées fournissant des soins en établissement à des femmes.

Participants : La totalité des 119 résidentes (âgées de 71 à 103 ans, âge moyen : 87,5 ans).

Intervention : Mise en oeuvre d'une directive de soins complets de santé et suivi après un an.

Mesure des résultats : Choix du traitement par les résidentes, respect de la directive, nombre d'admissions à l'hôpital et durée de l'hospitalisation, nombre de décès et lieux de survenue.

Résultats : Quatre-vingt-dix résidentes (76 %) ont rempli la directive. Advenant une

Dr. Molloy is assistant professor of medicine and a consultant geriatrician, Division of Geriatrics, Department of Medicine, and Dr. Guyatt associate professor, departments of Medicine and of Clinical Epidemiology and Biostatistics, McMaster University, Hamilton, Ont. Drs. Molloy and Guyatt are career scientists of the Ontario Ministry of Health.

Reprint requests to: Dr. D. William Molloy, Henderson General Division, Hamilton Civic Hospitals, 711 Concession St., Hamilton, ON L8V 1C3

maladie réversible menaçant la vie de la malade, 34, 24, 11 et 21 résidentes ont demandé, dans l'ordre, des soins de soutien, de durée limitée, maximums et intensifs. Dans l'éventualité d'une maladie réversible, les nombres étaient, dans l'ordre, 75, 12, 3 et 0. En cas d'arrêt cardiaque, 88 % ont demandé que l'on ne procède pas à la réanimation cardio-respiratoire. Neuf décès ont eu lieu au cours de l'année précédant l'adoption de la directive, un au foyer et huit à l'hôpital. Un an après l'adoption de la directive, 17 décès étaient survenus, 11 au foyer et 6 à l'hôpital. La durée moyenne d'hospitalisation était significativement moins élevée au cours de cette dernière année que pendant l'année précédant la mise en oeuvre ($p < 0,001$).

Conclusions : Cette directive innovatrice de soins de santé semble être faisable, pratique et bien accueillie par les résidentes, leur famille et les professionnels de la santé. D'autres études sont nécessaires pour établir la généralisation et la reproductibilité des données chez d'autres personnes âgées en établissement, chez des malades chroniques et dans la collectivité en général.

Recent advances in medical technology have increased our capacity to sustain life despite debilitating illness, but the use of medical technology to prolong life may sometimes be problematic.¹⁻³ For example, the care of incompetent elderly patients presents one of the most difficult ethical problems faced by physicians today.^{4,5} The patient's quality of life,^{6,7} the costs of health care,^{8,9} legal factors,^{10,11} the opinions of the next of kin,¹²⁻¹⁴ institutional policies¹⁵ and prevailing ethical and social norms¹⁶⁻¹⁹ may be considered when physicians make decisions about the care of such patients, decisions that will determine the proportion of health care resources to be allocated.^{20,21}

Concerns about the use of technology in the care of elderly people have led to the development of a variety of advance directives.²²⁻²⁵ Directives allow people to designate an advocate who will make health care decisions on their behalf (proxy directive) or to give instructions about the type of care they want if they become incompetent. Health care directives are currently supported by physicians^{16,26} and the public.²⁷⁻²⁹

In a recent survey of attitudes toward health care directives most elderly people reported that they would complete directives if given the opportunity.²⁷ Widespread use of this innovative approach to health care may improve patient autonomy, reduce health care costs, minimize unnecessary treatments and lower stress and conflict among family members and health care professionals, who are often forced to make difficult decisions.^{28,29}

Despite these potential benefits several questions remain: What proportion of elderly people would complete a directive if given the opportunity? Would there be difficulties with families, physicians or other health care professionals if directives were completed? What would happen if patients changed their mind during an illness and wanted to alter their directive?

In this study we introduced the residents of a home for the aged to a new and comprehensive health care directive (a) to determine whether they

would complete it, (b) to document their choices of health care in the event of cardiac arrest and reversible and irreversible life-threatening illness, (c) to find out if they would comply with the directive and (d) to compare the number of hospital admissions, the length of hospital stay, and the number of deaths and their location during the year before and after the directive was introduced.

Methods

Subjects

Idlewyld Manor, Hamilton, Ont., provides residential care to elderly women. About 80% have their own room, are independent in the activities of daily living and are provided with meals and medications. In a second wing more care is provided to the remaining 20% who need it.

The directive

The *Let Me Decide* directive is a comprehensive instrument that allows people to choose from four treatment options in the event of life-threatening illness.²³ The first option is supportive care, which would maintain comfort. It is equivalent to palliative care. The second option, limited care, would provide an intravenous line, antibiotics and a range of noninvasive investigations and treatments short of elective surgery. With maximum care patients may receive emergency surgery, if necessary. These patients are not candidates for intensive care and would not be given mechanical ventilation except during surgery. Under the final option, intensive care, all treatments and investigations are acceptable, including mechanical ventilation, central venous catheterization, transplantations, dialysis and biopsies. The directive also has a section on whether patients wish to receive cardiopulmonary resuscitation (CPR) in the event of cardiac arrest.

Residents chose a treatment option for reversible and irreversible life-threatening illness. Revers-

ible illness was defined as one that could be completely cured (e.g., pneumonia and ulcers). Irreversible illness was defined as one that left a permanent disability (e.g., hemiparesis after a stroke or impaired cognition due to Alzheimer's disease). Residents were encouraged to discuss what they considered to be reversible and irreversible illnesses. They were also asked to state their wishes concerning blood transfusion, postmortem examination and organ donation.

Introduction of the directive

In August 1989 all the residents and their families were invited to attend an introductory talk on the directive. The directive was presented, some of the terminology defined and a general discussion initiated. The residents were given a copy of the directive and advised to discuss it with their family or friends before completing it.

Six volunteer facilitators were given a 3-hour seminar on the use of the directive and trained to assist the residents to complete it. Four of the facilitators were retired nurses or social workers, and two were nurses at Idlewyld Manor. After the training seminar each facilitator was tested on her basic knowledge of the terms and conditions of the directive. Mock interviews were conducted and common situations and scenarios role-played until the facilitator was able to present the directive and appropriately answer possible common questions.

Over the next 4 to 6 weeks the facilitators met with all the residents to discuss whether they wanted to complete the directive and to answer questions. The residents were advised to choose an advocate to cosign the directive and to represent them should they become incompetent. The advocate was usually a family member or friend who lived nearby and was in regular contact; in essence, he or she was given power of attorney for the resident's health care.

The facilitators encouraged the residents to discuss their feelings and concerns with their advocates and inform them of their wishes for treatment in the event of cardiac arrest, reversible and irreversible life-threatening illness. After 1 to 2 weeks a meeting was arranged between the resident, the resident's advocate and a facilitator to discuss the directive and any further questions.

It was suggested that the resident and her advocate review with the family physician the decisions made and obtain his or her signature on the directive. A copy of the completed and signed directive was kept by each party, and two copies were placed in the resident's chart.

During the year after the directive was implemented one of the facilitators met with all new residents and introduced them to the document. The

nursing staff routinely reviewed and updated the directive with any resident who survived a serious medical event or wished to change her treatment option. In September and October 1990 a facilitator met with all the residents who had completed directives to discuss and update their treatment options. If a resident did not want to make changes the directive was cosigned by her and the facilitator. However, if the resident did wish to make changes they were discussed again with the advocate and the family physician, who then cosigned the documented changes.

Data collection

The director of nursing routinely kept a detailed record of all significant illnesses and the circumstances of all deaths. The dates of each hospital admission and return to the home were documented. Comparisons were made of the information recorded between Oct. 1, 1988, and Sept. 30, 1989 (the period before the directive was introduced) and that recorded between Oct. 1, 1989, and Sept. 30, 1990 (the period after the directive was introduced).

Statistical analysis

The proportions of patients who died in hospital over the 2 years were compared by means of the Fisher's exact test. The mean numbers of days spent in hospital for each admission were compared with the Student's unpaired *t*-test.

Results

During the year after the directive program was implemented 119 women were residents at Idlewyld Manor; 90 women, aged 71 to 103 (mean 87.5) years, completed the directive. In that period 17 patients died, and 1 moved to a nursing home. At the time of the annual review (September 1990) there were 101 residents, 81 of whom had completed the directive. Of the other 20 women 7 refused to complete the directive, 5 were incompetent but their families did not complete it for them, 3 were incompetent and had no relatives, 3 had a living will and did not want to change it, and 2 were new residents who had not been approached at the time of the review. Table 1 presents the original choices of the residents who completed the directive and their updated choices in September 1990. There were 11 changes in the level of care chosen: two residents opted for more care during reversible illness and nine for less care during reversible or irreversible illness. One resident changed her wish for CPR to a request for no CPR, and one decided to request CPR in the case of reversible illness.

Table 2 provides the location in which the deaths occurred and the details of hospital admissions during the years before and after the introduction of the directive. The numbers of residents who died in hospital during these 2 years were not significantly different. The pattern of where deaths occurred changed after the program was implemented: 13% of the deaths occurred in the home during the year before implementation and 63% during the year after. In addition, the number of days residents spent in hospital decreased after the implementation. This reduction was very unlikely to have occurred by chance ($p < 0.001$).

Seven of the 11 who died in the home during the year after the directive was introduced had completed the directive; 5 had requested supportive care in the event of irreversible illness, and 2 had requested limited care. All seven asked that no CPR be done in the event of cardiac arrest. None changed her choice when an acute life-threatening illness developed. The number of hospital admissions was greater in the year following implementation of the directive, but

because the length of stay was shorter the total number of nights spent in hospital was less.

Discussion

This study suggests that health care directives are accepted by elderly women in a home for the aged. They were completed by more than 80% of the residents and their families. Although most (83%) of the residents requested supportive care in the event of irreversible illness there was a broad range of choices in the event of reversible illness. In general, once the directive had been completed the residents did not change their mind after a serious illness or at annual follow-up.

The changes in the pattern of where the deaths occurred and the number of hospital days may have been due to unknown changes in the hospital programs or in the way the residents were treated.

The study had a number of limitations. First, it was a descriptive study with a before-after design and was subject to the biases of such a design. Any

Table 1: Choices for treatment of life-threatening illness and for cardiopulmonary resuscitation (CPR) by 90 residents of a home for the aged on initial completion of a health care directive and at 1-year review

Illness; treatment choice	At initial completion, no. of residents	At 1-year review			
		No. of residents		No. of deaths	No. of incomplete directives
		Same choice	Different choice		
Reversible					
Supportive (supp)	34	29	1 (max)	4	—
Limited (lim)	24	17	3 (supp)	3	1
Maximum (max)	11	8	1 (ICU)	2	—
Intensive care (ICU)	21	17	2 (supp) 2 (max)	—	—
CPR requested (CPR)	16	15	1 (NCPR)	—	—
No CPR requested (NCPR)	74	63	1 (CPR)	9	1
Irreversible					
Supp	75	68	—	6	1
Lim	12	7	2 (supp)	3	—
Max	3	3	—	—	—
ICU	—	—	—	—	—
CPR	11	10	1 (NCPR)	—	—
NCPR	79	69	—	9	1

Table 2: Deaths and hospital admissions before and after introduction of the health care directive

Variable	Before (n = 115)	After (n = 119)
No. of deaths		
In the home	1	11
In hospital	8	6
No. of hospital admissions*	24	33
Total no. of nights in hospital	562	383
Mean no. of nights per admission (and standard deviation)	23.4 (25.2)	11.6 (10.9)

*Any stay in hospital for more than one night.

changes in health care practice in the home or in the local hospitals that were unrelated to the directive may have affected the pattern of hospital admissions. It is plausible that in part, at least, the directive may have been responsible for the changes seen. However, we have no information about the decision-making process that determined whether residents would die at the home or in hospital, and thus any inference about the effect of the directive is weak. To demonstrate a causal connection would require a randomized trial.

A second limitation was the inclusion of only women in a residential home. Further study is needed to confirm that our data can be generalized to other elderly people in institutions, to chronically ill patients or to the community at large.

Third, no attempt was made to determine the influence of different facilitators on the choices made by the residents. However, the facilitators reported that most of the residents discussed treatment choices with their advocates; the facilitators were not asked to participate.

Despite these limitations the study provides valuable information about the use of health care directives in this population. The results suggest that comprehensive health care directives are acceptable. Furthermore, the residents had distinctly different choices about CPR in the event of cardiac arrest and the desired level of care for reversible and irreversible illnesses. This study supports the argument that elderly people want to participate in their own health care decisions and will complete comprehensive health care directives if given the opportunity. It also supports the notion that health care must be individualized.

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References

1. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research: *Deciding to Forgo Life-Sustaining Treatment: a Report on the Ethical, Medical and Legal Issues in Treatment Decisions*, US Govt Printing Office, Washington, 1983
2. *OMA Guidelines on Decision-making in the Treatment and Care of the Terminally Ill*, Ontario Medical Association, Toronto, 1990: 4-17
3. Molloy DW, Clarnette R, Braun EA et al: Decision making in the incompetent elderly: "the daughter from California syndrome." *J Am Geriatr Soc* 1991; 39: 396-399
4. Smedira NG, Evans BH, Gras LS et al: Withholding and withdrawal of life support from the critically ill. *N Engl J Med* 1990; 322: 309-315
5. Rouse F, Dornbrand L: Family decision-making on trial: Who decides for the incompetent patients? *Ibid*: 1228-1232
6. Pearlman RA, Jonsen A: The use of quality-of-life considerations in medical decision-making. *J Am Geriatr Soc* 1985; 33: 344-352
7. Powell LM, Moss M, Glicksman A: The quality of the last year of life of older persons. *Milbank Q* 1990; 68: 1-28
8. Helwig D: Stop wasting health care dollars on dying seniors, physician says. *Can Med Assoc J* 1990; 143: 653-654
9. Jecker NS, Pearlman RA: Ethical constraints on rationing medical care by age. *J Am Geriatr Soc* 1989; 37: 1067-1075
10. Glover JJ, Mastroianni A, Anderson KR et al: Abridged brief as amicus curiae of the American Geriatrics Society. *J Am Geriatr Soc* 1990; 38: 570-576
11. McClung JA, Kamer RS: Implication of New York's Do-Not-Resuscitate Law. *N Engl J Med* 1990; 323: 270-272
12. Uhlmann RF, Pearlman RA, Cain KC: Physicians' and spouses' predictions of elderly patients' resuscitation preferences. *J Gerontol* 1988; 43: M115-M121
13. Zweibel NR, Cassel CK: Treatment choices at the end of life: a comparison of decisions by older patients and their physician-selected proxies. *Gerontologist* 1989; 29: 616-621
14. Tomlinson T, Howe K, Notman M et al: An empirical study of proxy consent for elderly persons. *Gerontologist* 1990; 30: 54-64
15. Miles SH, Singer PA, Seigler M: Conflicts between patients' wishes to forgo treatment and the policies of health care facilities. *N Engl J Med* 1989; 321: 48-50
16. Alemayehu E, Molloy DW, Guyatt GH et al: Variability in physicians' decisions on caring for chronically ill elderly patients: an international study. *Can Med Assoc J* 1991; 144: 1133-1138
17. Gillick MR: Limiting medical care: physicians' beliefs, physicians' behavior. *J Am Geriatr Soc* 1988; 36: 747-752
18. Eisenberg JM: Sociologic influences on decision-making by clinicians. *Ann Intern Med* 1979; 90: 957-964
19. Waxman HM, Astrom S, Norberg A et al: Conflicting attitudes toward euthanasia for severely demented patients of health care professionals in Sweden. *J Am Geriatr Soc* 1988; 36: 397-401
20. Levinsky NG: Age as a criterion for rationing health care. *N Engl J Med* 1990; 322: 1813-1816
21. Mustard JF: Aging and health: research, policy, and resource allocation. In Lewis SJ (ed): *Aging and Health: Linking Research and Public Policy*, Lewis Pubs Inc, Chelsea, Mich, 1989: 187-193
22. Emanuel LL, Emanuel EJ: The medical directive: a new comprehensive advance care document. *JAMA* 1989; 261: 3288-3293
23. Molloy DW, Mephram V: *Let Me Decide*, 2nd ed, McMaster U Pr, Hamilton, Ont, 1990
24. Eisendrath SJ, Jonsen AR: The living will: Help or hindrance? *JAMA* 1983; 249: 2054-2058
25. Clarnette RM, Molloy DW: Health care directives. In *The Annual of Medical Direction*, American Medical Directors Association, Columbia, Md, 1991: 48-51
26. Relman AS: Michigan's sensible "living will." *N Engl J Med* 1979; 300: 1270-1272
27. Molloy DW, Guyatt G, Alemayehu E et al: Treatment preferences, attitudes towards advance directives and concerns about health care in the general public. *Humane Med* (in press)
28. Davis M, Southerland LI, Garrett JM et al: A prospective study of advance directives for life-sustaining care. *N Engl J Med* 1991; 324: 882-888
29. Emanuel LL, Barry MJ, Stoeckle JD et al: Advance directives for medical care — a case for greater use. *N Engl J Med* 1991; 324: 889-895