

Canadian outpatients and advance directives: poor knowledge and little experience but positive attitudes

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Objective: To examine the knowledge of, previous experience with, attitudes toward and perceived barriers to completing advance directives among outpatients at two general medicine clinics.

Design: Cross-sectional questionnaire administered in face-to-face structured interviews.

Setting: General internal-medicine outpatient clinics at a university teaching hospital.

Patients: One hundred and five adult outpatients who could communicate in spoken English and who consented to be interviewed.

Results: Of 167 patients approached, 58 were excluded because they could not communicate in spoken English, and 4 refused to participate. Of the remaining 105 patients, 17 (16%) knew about living wills, 12 (11%) about durable powers of attorney for health care and 4 (4%) about advance directives. Twenty-three (22%) had thought about their preferences for life-sustaining treatment, 20 (19%) had discussed them, none had written them down, and 45 (43%) had thought about choosing a proxy. Sixty-one (58%) wanted to think about their preferences for treatment, 65 (62%) wanted to discuss them, 32 (30%) wanted to write them down, and 80 (76%) wanted to choose a proxy. The perceived barriers to completing an advance directive were inability to write, the belief that an advance directive was unnecessary, a fatalistic attitude, previous discussion of preferences, a desire to leave the decision to doctors, uncertainty about preferences, a desire to discuss preferences rather than document them, a desire to wait until the situation arose, a desire to write down preferences in the future and a desire to avoid thinking about preferences or advance directives. Respondents with more knowledge of life-sustaining treatments were more likely to want to complete an advance directive.

Conclusions: Outpatients have positive attitudes toward advance directives, but their knowledge and experience are limited. These data underscore the need for patient education and for policies to eliminate the barriers to completing advance directives that patients face.

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Objectif : Examiner, chez des patients en consultation externe de cliniques de médecine générale, la connaissance des directives préalables, leur expérience antérieure et leur attitude à cet égard, ainsi que les obstacles perçus.

Conception : Questionnaire transversal administré au cours d'entrevues personnelles structurées.

Contexte : Cliniques externes de médecine interne générale à un hôpital d'enseignement universitaire.

Patients : Cent cinq adultes en consultation externe capables de communiquer verbalement en anglais et qui ont consenti à être interviewés.

Résultats : Parmi les 167 patients à qui l'on a demandé de participer, 58 ont été rejetés parce qu'ils ne pouvaient communiquer verbalement en anglais et 4 ont refusé de participer. Parmi les 105 patients restants, 17 (16 %) connaissaient le testament de vie, 12 (11 %), les procurations de longue durée pour soins de santé et 4 (4 %), les directives préalables. Vingt-trois (22 %) avaient réfléchi à leurs préférences quant aux traitements de maintien de la vie, 20 (19 %) en avaient discuté, aucun n'avait préparé d'instructions écrites et 45 (43 %) avaient pensé à choisir un mandataire. Soixante-et-un (58 %) voulaient réfléchir à leurs préférences quant aux traitements, 65 (62 %) voulaient en discuter, 32 (30 %) voulaient les consigner par écrit et 80 (76 %) voulaient choisir un mandataire. Parmi les obstacles perçus qui empêchaient de donner des directives préalables, mentionnons l'incapacité d'écrire, la perception que les directives préalables ne sont pas nécessaires, le fatalisme, le fait d'avoir déjà discuté de préférences, de vouloir laisser la décision au médecin, de ne pas connaître ses préférences, de vouloir discuter de ses préférences avant de donner des directives, de vouloir attendre que le problème se pose, de vouloir consigner par écrit des préférences à l'avenir, de ne pas vouloir réfléchir à ses préférences ou à des directives préalables. Les patients qui connaissaient davantage les traitements de maintien de la vie étaient plus susceptibles de vouloir donner des directives préalables.

Conclusions : Les patients en consultation externe ont une attitude positive face aux directives préalables, mais ils en ont une connaissance et une expérience limitées. Les données montrent qu'il faut informer les patients et établir des politiques afin de supprimer les obstacles que doivent surmonter les patients pour donner des directives préalables.

Advance directives project the life-sustaining treatment preferences of competent persons into future states of incompetence.¹ Manitoba and Ontario have recently passed legislation recognizing both instruction and proxy directives.^{2,3} In Alberta and Saskatchewan, law reform commissions have produced reports supporting advance directives.^{4,5}

Several studies in the United States have found that patients usually express a positive attitude toward discussing life-sustaining treatment and completing advance directives, but their knowledge and experience are limited.⁶⁻¹⁸ However, because of the public impact of landmark US legal cases such as *Re Quinlan*¹⁹ and *Cruzan v Director, Missouri Department of Health*²⁰ and of the US *Patient Self-Determination Act*,²¹ it may not be possible to generalize from data obtained in the United States to the situation in Canada. Although two studies have examined public opinion in Canada regarding advance directives^{22,23} and another has examined the use of an advance directive in a home for the aged,²⁴ we are unaware of any studies of the knowledge, experience and attitudes of Canadian patients regarding this subject.

The specific questions of this study were the

following: What do patients know about life-sustaining treatments and advance directives? Have patients considered, discussed or documented their preferences for life-sustaining treatments or thought about choosing a proxy? Do patients want to consider, discuss or document their preferences for life-sustaining treatments or choose a proxy? What barriers do patients perceive to completing an advance directive? What relationships, if any, exist among patients' characteristics and their knowledge, experience and attitudes regarding advance directives?

Methods

The design of this study was a cross-sectional questionnaire survey consisting of face-to-face structured interviews with adults (18 years of age or older) visiting two general internal-medicine outpatient clinics at the Toronto Hospital (Western Division), Toronto, from August to December 1991. The patients were approached in the waiting room of the clinic before their appointments. Patients were excluded if they were unable to communicate in spoken English, refused to be interviewed or were visiting the clinics for the first time. All patients were interviewed by one of us (M.S.).

The survey contained 89 questions. First, patients' knowledge was evaluated by their ability to provide a meaningful explanation of life-sustaining treatments and advance directives; the level of knowledge was judged by the interviewer. Then, patients were given brief descriptions of life-sustaining treatments and advance directives (Appendix 1). Next, the experience and attitudes of the patients were examined. Perceived barriers were elicited with open-ended questions; the responses were subjected to content analysis by the two investigators. Finally, demographic (age, sex, education, religion and income) and clinical (physical status, health and previous experience with admission to hospital and disease) information was sought. The questionnaire was examined for face and content validity by a panel of experts in philosophy, law, medicine and bioethics. (A copy of the questionnaire is available from the authors upon request.) A pilot study of 11 patients was performed to determine the feasibility of using the questionnaire; analysis of the pilot data helped in the elimination, modification and addition of items for the final version of the questionnaire.

Univariate data were analysed with simple descriptive statistics. Because some of the respondents did not answer some of the questions, the denominator for the proportions was sometimes less than the total number of respondents. Bivariate data were analysed with the chi-square and the Wilcoxon rank sums tests and the *t*-test, as appropriate; $p < 0.05$ was considered statistically significant. The study was approved by the Human Subjects Review Committee of the University of Toronto.

Results

Patient characteristics

Of 167 patients approached, 58 were excluded because they could not communicate in spoken English, and 4 refused to participate. The 105 respondents consisted of 41 (39%) women and 64 (61%) men. The median age was 67 years (range, 21 to 91 years). Fifty-six (53%) were married, 23 (22%) had never married, and 26 (25%) were widowed, divorced or separated. Forty-five (43%) were Catholic, 33 (31%) Protestant, 9 (9%) Greek Orthodox, 3 (3%) Jewish and 2 (2%) Muslim; 13 (12%) had another or no religion. Fifty-eight (55%) had graduated from high school or a postsecondary institution, 40 (38%) had graduated from elementary school, and 7 (7%) had no formal education. Annual income was less than \$15 000 for 52 (50%) of the respondents, between \$15 000 and \$30 000 for 20 (19%) and higher than \$30 000 for 14 (13%); 19 (18%) did not disclose their income. During the previous 12 months 77 (73%) had been admitted to hospital and

28 (27%) had not; 60 (57%) had at some time had a serious illness or operation, 43 (41%) had not, and 2 (2%) were unsure whether they had. Forty (38%) had been in an intensive care unit at some time and 65 (62%) had not. Fifty-four (51%) perceived their health as good to excellent, 33 (31%) perceived it as fair and 18 (17%) perceived it as poor. During the previous 4 weeks 40 (38%) had suffered moderate to severe physical pain, 31 (30%) mild to very mild pain and 34 (32%) no pain.

Knowledge

Knowledge of life-sustaining treatments was limited: 67 (64%) of the respondents could define "intensive care," 53 (50%) "respirator" or "breathing machine," 52 (50%) "cardiopulmonary resuscitation" or "CPR," 41 (39%) "kidney dialysis" and 37 (35%) "artificial nutrition" or "tube feeding." Knowledge about living wills, durable powers of attorney for health care and advance directives was more limited: 17 (16%), 12 (11%) and 4 (4%) of the respondents respectively could define these terms.

Experience

Experience with advance consideration, discussion and directives for life-sustaining treatment was also limited. Twenty-three (22%) of the respondents had thought about their life-sustaining treatment preferences, and 20 (19%) had discussed these preferences with someone, but none had written them down. Forty-five (43%) had thought about choosing a proxy; of these, 21 (47%) had discussed their preferences with the potential proxy, and 2 (4%) had documented their choice of proxy. The patients had discussed their preferences most frequently with friends, spouses and children (in that order). The spouse, a child and a friend (in that order) had been chosen most frequently as the proxy.

Attitudes

The respondents expressed a positive attitude toward advance consideration, discussion and directives (Table 1). They wanted to discuss their preferences most frequently with doctors, the spouse and children (in that order). The spouse, a child or a doctor (in that order) was the most likely choice for the proxy among those who had not already chosen one. Of the 66 respondents who expressed an opinion about who should initiate discussions about life-sustaining treatment, 41 (62%) thought that doctors should. Fifty-one (49%) preferred proxy directives, 9 (9%) instruction directives, 25 (24%) both types and 5 (5%) neither; 15 (14%) were not sure what type of directive they preferred. One hundred

and one of the respondents suggested appropriate times to discuss advance directives: 67 (66%) suggested during a routine check-up at a doctor's office, 56 (55%) the time of admission to hospital, 50 (50%) the onset of a serious illness and 39 (39%) the time of admission to a nursing home.

Perceived barriers

Patients who did not want to think about, discuss or document their life-sustaining treatment preferences or did not want to choose a proxy were further questioned about the barriers that they perceived to doing so. Reasons for not wanting to think about or discuss preferences (in decreasing order of frequency) included a fatalistic attitude, a wish to leave the decision making to doctors and the family and a wish to postpone the issue to a future time or to when the situation arose. Reasons for not wanting to document preferences (in decreasing order of frequency) included an inability to write, the belief that such documentation was unnecessary, a fatalistic attitude, previous discussion of preferences, a desire to leave the decision to doctors, uncertainty about preferences and a desire to discuss preferences rather than document them. Reasons for not wanting to choose a proxy included not knowing anyone suitable and preferring to make such decisions alone.

Bivariate associations

The respondents with higher levels of education

were more likely to know about life-sustaining treatments, living wills and durable powers of attorney for health care and to want to document their preferences and choice of proxy. The respondents who knew about intensive care were more likely to want to discuss their treatment preferences. Those who knew about intensive care or CPR were more likely to want to write down their treatment preferences and to document their choice of proxy.

Discussion

Patients' knowledge of life-sustaining treatments and advance directives was limited. The most widely known term was "intensive care" and the least widely known "advance directive." Moreover, greater knowledge about life-sustaining treatments was associated with a more positive attitude toward advance directives. Therefore, if legislators and policymakers want to promote the appropriate use of advance directives, they should develop and fund patient and public education programs. Furthermore, health care providers who want to discuss advance directives with their patients should begin by clearly defining the terms.

The patients' experience with advance discussions and directives was also limited. The most extensive area of experience was consideration of appointing a proxy (45 [43%] had considered this step). It is reasonable to speculate that lack of experience is at least partially attributable to a lack of knowledge about life-sustaining treatment and

Table 1: Attitudes of 105 outpatients toward advance directives

Question	Response; no. (and %) of patients		
	Yes	No	Not sure
Do you want to think about your preferences for life-sustaining treatments?	61 (58%)	24 (23%)	20 (19%)
Do you want to discuss with someone your preferences for life-sustaining treatments?	65 (62%)	28 (27%)	12 (11%)
Do you want to write down your preferences regarding life-sustaining treatments in a document?	32 (30%)	57 (54%)	16 (15%)
Do you want to choose someone else to decide on your behalf regarding life-sustaining treatments?	80 (76%)	18 (17%)	7 (7%)
Do you want to discuss your decision with that person?*	76 (89%)	5 (6%)	4 (5%)
Do you want to write down your decision to choose that person?*	34 (42%)	29 (36%)	18 (22%)

Note: Percentages may not add to 100% because of rounding.
*Patients who did not want to choose a proxy were not asked to answer these questions. Of the 87 people who were asked these questions, not all chose to answer.

advance directives. If such is the case, public education programs may be helpful in overcoming patients' reluctance to consider and complete such directives.

Although their knowledge and experience were limited, the respondents expressed a positive attitude toward consideration of and discussions about life-sustaining treatment. These results agree with those of previous studies^{14,16,18} and suggest that the time may be ripe to introduce advance directives in Canada.

The respondents were more willing to choose a proxy or to discuss their preferences than to document (at some future time) their choice of proxy or preferences. They also preferred proxy directives to instruction directives or combined proxy and instruction directives. These findings suggest that, in addition to public education, flexibility and choice by the patient in the selection of advance directive format are needed.

The patients wanted to discuss their treatment preferences with their doctors, their spouses and their children. More than half also thought that doctors should initiate discussions about life-sustaining treatment and that a routine check-up was an appropriate time for such discussions. These findings have implications for both drafting policies and designing educational activities in this area. For instance, institutional policies should encourage physicians to engage patients in discussions about advance directives. Educational programs for physicians may also be needed.

The respondents identified several barriers to considering, discussing and completing advance directives. Some of the perceived barriers, such as fatalism, a lack of desire to think about life-sustaining treatments and a wish to leave the decision making to others, are principally matters of attitude and preference. Others, such as lack of a regular doctor, a wish for everything possible to be done to sustain life, illiteracy and a desire to wait until the situation arose, could be overcome through education or other policy measures.

Respondents with higher levels of education and better knowledge of intensive care and CPR were more likely to want to discuss or document their preferences or choice of proxy. These results underscore the potentially important role of public education programs.

This study had six main limitations. First, our subjects were relatively old and of a low socioeconomic status; therefore, it may not be possible to generalize from these results to other populations with different demographic characteristics. Second, the respondents' views may differ from those of the outpatients who chose not to respond (nonresponse bias). Third, the respondents' own reports of ex-

perience may not be reliable (recall bias). Fourth, the answers provided by respondents about their attitudes may have been those that they thought the investigator wanted to hear rather than their sincere responses (social desirability bias). Fifth, the statistical power of the study to detect bivariate associations was limited by the sample size, and the associations were not hypothesized *a priori*. Finally, we do not imply that patients' responses dictate the right action (which would be the naturalistic fallacy of deriving moral conclusions from nonmoral premises — of deriving "what ought to be" from "what is").

Conclusions

The outpatients in our study had poor knowledge and little experience but positive attitudes regarding advance directives. These findings are similar to those of a recent study of Ontario family physicians.²⁵ Physicians and patients should begin to communicate better with each other regarding the use of life-sustaining treatments and advance directives.

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Appendix 1: Descriptions of life-sustaining treatments and advance directives given to patients before they were asked about their experience and attitudes

Life-sustaining treatments are medical treatments for very sick patients. If a patient needs one of these treatments but does not get it, he or she will die. Some examples of these treatments are tube feeding, heart resuscitation or cardiopulmonary resuscitation, and connection to a breathing machine.

Tube feeding is used when a patient is not able to eat or drink by mouth. A tube is placed through the nose into the stomach or directly into the stomach through the skin. Fluids and nutrients are given through this tube.

Heart resuscitation is used to restart the heart when it stops beating. The procedure involves chest compression over the heart, artificial breathing through a tube inserted down the throat, electric shocks to the heart and administration of various drugs.

A breathing machine is used when the lungs are not able to deliver enough oxygen to the blood. The procedure involves placing a tube down the throat and hooking the tube up to a machine that breathes for the patient.

Advance directives: Because of an accident or an illness a patient may not be able to tell the doctor what life-sustaining treatments he or she wants or does not want. Therefore, the patient may want to discuss preferences about life-sustaining treatments with someone beforehand and write down these preferences. The patient may also want to choose someone that he or she trusts to make decisions about life-sustaining treatments on his or her behalf.

Suffer, die or get well

I shall always ask what real good the art of medicine has done to men. Some of those whom it cures would die, to be sure, but millions whom it kills would live. Sensible reader, do not invest in that lottery where the chances are so heavily against you. Suffer, die, or get well, but in any case live to your last hour.

— Jean Jacques Rousseau (1712-1778)
Émele, Bk. II