Public Opinion Regarding Consent to Treatment

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Objective: To examine public opinion regarding certain elements of consent: disclosure, advance directives, substitute decisions, emergency treatment, and advocacy.

Design: Cross-sectional random-digit-dialing telephonic survey.

Setting: General public.

Participants: One thousand randomly-selected adults living in Ontario.

Interventions: None.

Main Outcome Measures: Self-reported attitudes and behaviors.

Results: Of 5,708 telephone numbers drawn, 641 were nonvalid or non-residential, 1,283 were not in service, 1,068 had no answer, a busy line, or an unavailable respondent, 147 subjects had a language barrier, 1,497 subjects refused, 72 interviews were incomplete, and 1,000 interviews were completed. With regard to disclosure, 33% of respondents said that a doctor should withhold information from a patient if asked to do so by the patient’s family. With regard to advance directives, 36% of respondents had had advance discussions with their families, and 12% had completed a living will. With regard to substitute decisions, 77% of respondents said that they would want their wishes followed if they were unable to make medical decisions for themselves; 58% wanted their spouse or partner to make such decisions for them. With regard to emergency treatment, 48% of respondents stated that a doctor should give a life-saving blood transfusion to an unconscious adult carrying a card stating that blood transfusion was against his or her religious beliefs. With regard to advocacy, 78% of respondents supported mandatory advocacy services for serious health decisions such as whether to have heart surgery; 33% supported advocacy services for less serious decisions such as whether to have a dental filling.

Conclusions: These data highlight the need to reconsider legislative provisions regarding and/or target public education programs toward specific consent-related issues including disclosure, advance directives, substitute decisions, emergency treatment, and advocacy. J Am Geriatr Soc 41: 112–116, 1993

In 1991 the Government of Ontario introduced new legislation on consent to treatment.1–3 The Ontario legislation—the Consent to Treatment Act, the Substitute Decisions Act, and the Advocacy Act—is broad in scope. The legislation codifies the common law requirement for informed consent and, through regulations, will stipulate procedures to determine capacity. It sets out a hierarchy of substitute decision-makers for incapable patients and establishes how substitute decisions should be made by granting priority to expressed wishes over best interests. The legislation recognizes advance directives; if enacted, it would make Ontario the fourth province in Canada to do so since Nova Scotia4 and Québec5 have legislation recognizing proxy directives, and Manitoba6 has recently passed legislation recognizing proxy and instruction directives. (In contrast to the US Patient Self-Determination Act,7 the Ontario legislation does not require health facilities to routinely inform patients about their right to complete an advance directive). The legislation recognizes an emergency exception to the requirement for informed consent, except when the prior wishes of the patient suggest that the patient would not want treatment. Perhaps the most controversial feature of the legislation is the establishment of a province-wide patient advocacy program. Advocates would serve as “rights advisors” to persons declared incapable of giving consent to treatment; they would explain the effect of being declared incapable (ie, that the patient has lost the right to make health care decisions for him/herself) and advise incapable patients of their right to appeal the declaration of incapacity to a review board established by the legislation.

To address some controversial issues related to the legislation,8,9 we performed a public opinion poll. Our goal was to identify needs for public education or legislative provisions that might require reconsideration. Although we developed the poll from the framework of the Ontario legislation, the fundamental issues addressed are relevant to all jurisdictions where consent is based on principles of Anglo-American law.

METHODS

The research design was a cross-sectional survey of 1,000 adults living in Ontario and was conducted by telephone from September 5 to September 25, 1991. The questions for the poll were developed from the proposed legislation, with particular emphasis on one of the bills.2 To ensure content validity, we circulated draft questions to government lawyers who wrote the legislation and made revisions based on their comments. We pilot tested the questions by telephone on a sample of 25 respondents and made further minor revisions.

The sampling method was designed to complete 1,000 interviews within households randomly selected.
across the province of Ontario. The sample was stratified in proportion to the populations of six regions within the province and five community-size groups within each region. A modified Waksberg-Mitofsky sample selection technique was used.\textsuperscript{10, 11} Telephone numbers were selected from the most recently published telephone directories. These numbers act as "seeds" from which the sample is actually generated. The original "seed" telephone number is not used in the sample. The Waksberg-Mitofsky sample selection technique ensures that both unlisted numbers and numbers listed after the directory publication are included in the sample. A minimum of five calls were made to a household before classifying it as a "no answer." From within each multi-person household contacted, respondents 18 years of age and older were screened for random selection using the "Most Recent Birthday" method.\textsuperscript{12} The use of this technique produces results that are as valid and effective as enumerating all persons within a household and selecting one randomly. Field supervisors were present at all times to ensure accurate interviewing and recording of responses; 10% of each interviewer's work was monitored for quality control.

Univariate data are shown as proportions. For bivariate comparisons, we used the chi square test if both variables contained nominal data and the Wilcoxon rank sums test if either variable contained ordinal data. Because we made 11 bivariate comparisons for each question (age, gender, income, employment status, home ownership, union membership, political preference, religion, education, marital status, and ethnicity), we considered $P \leq 0.005$ as statistically significant. A sample of 1,000 persons within the population of Ontario produces a sampling error of ±3.1%. This study was approved by the Human Subjects Review Committee of the University of Toronto.

RESULTS

Of 5,708 telephone numbers drawn, 641 were non-valid or non-residential, 1,283 were not in service, 1,068 had no answer, a busy line or an unavailable respondent, 147 subjects had a language barrier, 1,497 refused, 72 interviews were incomplete, and 1,000 interviews were completed. Of the 1,000 respondents, 50% were female, 60% had education beyond high school, 59% were married, and 59% were working full time. The age distribution of respondents was as follows: 18–24 years, 13%; 25–34 years, 28%; 35–44 years, 28%; 45–54 years, 13%; 55–64 years, 10%; and ≥65, 8%.

Public attitudes towards disclosure are shown in Table 1. Overall, 44% of respondents said that withholding information from a patient was either a benefit to the patient or an appropriate response to a family request. Those respondents who agreed that it was sometimes a benefit to a patient for a doctor to withhold information listed the circumstances under which this might be so as follows: if the patient is psychologically or emotionally unstable (52%), if the illness is terminal or life-threatening (18%), if the patient is elderly (9%), if the patient may lose the will to live (5%), if the patient is a child (4%), other (11%); and don't know/no answer (12%). Factors associated with the belief that a doctor should withhold information from the patient at the family's request included: home ownership, religious affiliation, political preference other than the governing New Democratic Party, and retired work status. Factors associated with the belief that it was sometimes of benefit for a doctor to withhold information included older age and higher educational level. Factors associated with the belief that a doctor should withhold information if asked to do so by a patient's family included older age. We also asked respondents, "At what age do you think people should be allowed to visit doctors and receive treatment on their own without parental knowledge or consent?" The median response was 16 years (90% interquartile range, 12–19 years). Attitudes and behaviors towards advance decision making are shown in Table 2. Overall, 29% of respondents had an advance discussion but no living will, 5% had a living will but no advance discussion, 7% had both, and 58% had neither. Factors associated with the belief that people should have the right to request withholding or withdrawal of life-sustaining treatment included: older age, non-school employment status, and British ethnicity. Factors associated with advance discussions included older age, female gender, and married marital status. The proportion of respondents who had had advance discussions, stratified by age group, was as follows: 18–24 years, 20%; 25–34 years, 34%; 35–44 years, 38%; 45–54 years, 46%; 55–64 years, 43%; and ≥65 years, 48%. Factors associated with having completed a living will included older age and religious affiliation. The proportion of respondents who had completed a living will, stratified by age group, was as follows: 18–24 years, 3%; 25–35 years, 12%; 35–44 years, 11%; 45–54 years, 15%; 55–64 years, 16%; and ≥65 years, 18%. Choice of living will format was also associated with age; younger people tended to prefer combined proxy/instruction directives.

The attitudes of the public towards substitute decision making are shown in Table 3. Ten percent of respondents who had discussions with family members
TABLE 2. PUBLIC ATTITUDES AND BEHAVIORS TOWARD ADVANCE DECISION MAKING

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>DK/NA</th>
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<tbody>
<tr>
<td>Do you think that people should have the right to request the withholding or withdrawal of life-sustaining treatment?</td>
<td>85%</td>
<td>9%</td>
<td>6%</td>
</tr>
<tr>
<td>Have you discussed with your family what life-sustaining treatments you would or would not want if you became unable to make decisions for yourself?</td>
<td>36%</td>
<td>63%</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>A “living will” is a document you make to guide treatment decisions when you become unable to make these decisions for yourself. The “living will” may specify who shall make decisions for you and/or what life-sustaining treatments you do or do not wish to receive. Have you filled out a “living will”?</td>
<td>12%</td>
<td>88%</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Do you think a “living will” should include just the name of the person appointed to make decisions for you, just the life-sustaining treatments which you do or do not wish to receive, or both?</td>
<td>9%</td>
<td>3%</td>
<td>83%</td>
</tr>
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TABLE 3. PUBLIC ATTITUDES TOWARD SUBSTITUTE DECISION MAKING

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>DK/NA</th>
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<tr>
<td>If you became unable to make medical decisions for yourself because you were in a coma, but you had left wishes to guide your medical treatment, how should others make these decisions for you? Should they:</td>
<td>77%</td>
<td>6%</td>
<td>1%</td>
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<td>Follow the wishes you left</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Do what they think you really want</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do what they think is best for you</td>
<td></td>
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<tr>
<td>If you became unable to make medical decisions for yourself because you were in a coma, which one of the following individuals would you want to make these decisions for you?</td>
<td>58%</td>
<td>14%</td>
<td>10%</td>
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<td>Your spouse or partner</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Your parent</td>
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<td>Your doctor</td>
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<tr>
<td>Your child (16 or older)</td>
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<td>Your brother or sister</td>
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<td></td>
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<tr>
<td>A friend</td>
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<tr>
<td>A relative other than parent, child or sibling</td>
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<td>DK/NA</td>
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TABLE 4. PUBLIC ATTITUDES TOWARD EMERGENCY TREATMENT

<table>
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<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>DK/NA</th>
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<td>Suppose an unconscious adult was brought into an emergency room following a car accident. A doctor determined that if the patient’s life were to be saved, the patient would need a blood transfusion. However, the patient was carrying a card stating that blood transfusion was against his or her religious beliefs, and that he or she would not want it under any circumstances. Efforts to contact family members had failed. Do you think the doctor should or should not give a blood transfusion?</td>
<td>48%</td>
<td>45%</td>
<td>6%</td>
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<td>Should</td>
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<tr>
<td>Should not</td>
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and 13% of respondents who had completed living wills wanted others to do "what they think is best" if the patient became unable to make medical decisions. With regard to how substitute decisions should be made, women were more likely than men to want their wishes to be followed, and men were more likely than women to want others to do "what they think is best." The following factors were associated with the choice of a spouse or partner as substitute decision maker: married marital status, higher income, and non-school employment status. Older age was associated with choice of one's child (16 or older) as substitute decision maker.

Attitudes towards emergency treatment are shown in Table 4. Men and respondents with political preference other than the governing New Democratic Party were more likely to say the doctor should give the blood transfusion.

Public attitudes towards advocacy are shown in Table 5. Interestingly, 7.6% of respondents said the law should require advocacy for themselves but not for a family member, and 3.8% said the law should require it for a family member but not for themselves. A desire for advocacy in serious decisions was associated with female gender. A desire for advocacy "when it is you who become sick" was associated with lower educational level and younger age. A desire for advocacy "when it is a member of your family who becomes sick" was associated with younger age and lower income.

Other associations between respondent characteristics and their opinions were not significant.
TABLE 5. PUBLIC ATTITUDES TOWARD ADVOCACY

Suppose a person became sick, and a doctor determined that he/she was not mentally capable of making a particular health care decision. In each of the following circumstances, do you think the law should or should not require an individual called “an advocate” to meet with the sick person to explain that he/she had lost the right to make that health care decision and that someone else would be making it for him/her?...

<table>
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<th>Should</th>
<th>Should Not</th>
<th>DK/NA</th>
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<tr>
<td>When the health care decision is a serious one, for example, whether to have heart surgery.</td>
<td>78%</td>
<td>15%</td>
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<tr>
<td>When the health care decision is not a serious one, for example, whether to have a dental filling.</td>
<td>33%</td>
<td>63%</td>
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<tr>
<td>When it is you who becomes sick and incapable of making a particular health care decision.</td>
<td>65%</td>
<td>29%</td>
</tr>
<tr>
<td>When it is a member of your family who becomes sick and incapable of making a particular health care decision.</td>
<td>61%</td>
<td>33%</td>
</tr>
<tr>
<td>When the cost of providing the services of an advocate is paid by the government and therefore, could cause your taxes or the provincial deficit to go up.</td>
<td>61%</td>
<td>29%</td>
</tr>
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</table>

DISCUSSION

Public attitudes toward disclosure contrast with legal and ethical requirements. Forty-four percent of respondents in this poll agreed that there are circumstances under which physicians should withhold information from patients. Most often these circumstances were a family request to withhold information or psychological or emotional instability of the patient. These findings are in accord with a 1982 Harris Poll performed for the President’s Commission in which 49% of the public said that a physician could justifiably withhold information upon family request, and 52% said that the physician could justifiably withhold information that might make the patient anxious or upset. By contrast, the Commission concluded that physicians should withhold information “only when the harm of its disclosure is both highly probable and seriously disproportionate to the affair to (patient) self-determination.” A landmark informed consent case, Canterbury v. Spence, also restricts the therapeutic privilege of physicians to withhold information to situations “when risk disclosure poses such a threat of detriment to the patient as to become unethical or contraindicated from a medical point of view.” Ontario’s proposed consent legislation contains no provisions regarding therapeutic privilege. This discrepancy between public opinion and legal and ethical standards suggests one of two courses of action. On the one hand, it may highlight the need to educate the public about why the scope of therapeutic privilege should be limited. On the other hand, it may suggest that the emerging ethical and legal standards should themselves be reconsidered.

The data regarding advance decision making highlight the gap between positive attitudes toward decisions to forego treatments and actual advance discussions or directives. These data parallel results from a 1986 American Medical Association poll. Because advance discussions are three times as prevalent as directives, policy makers should not ignore the potential utility of promoting both through legislation. Also, because instruction and proxy directives are complementary, and because there is such strong public support for combined directives, it would be reasonable to recommend combined proxy/instruction directives as the advance directive of choice. Moreover, since it is likely that the gap between public support for advance directives and the actual use of advance directives will remain, other options should also be considered.

Substitute decision-making poses two questions: (1) Who should make decisions for incapable patients? and (2) How should these decisions be made? With regard to “who,” the poll results offer an empirical basis for legislation which, in the absence of an advance directive, ranks various parties in hierarchical order. Moreover, 10% of respondents want their doctor to make treatment decisions for them. From a legal and ethical perspective, these respondents are requesting physician paternalism and rejecting patient autonomy. This result has been shown in other studies. With regard to “how,” legal and ethical commentators rank the following standards in hierarchical order of descending priority: (1) advance directives (or clear wishes), (2) substituted judgment, and (3) best interests. The poll data show that the public do not completely agree with this ranking. While advance directives receive the highest approval rating, respondents prefer best interests to substituted judgment by a 10% margin. Moreover, 22% of respondents support either best interests or substituted judgment even when clear prior wishes are available. Again, these data show that there is less than universal agreement with current individualistic, autonomy-based standards for medical-ethical decision making.

The emergency exception to the requirement to obtain informed consent is well recognized. The exception is based on the grounds that a reasonable person would consent to treatment if he or she were able to do so. Recently, in the Ontario case of Malette v. Shulman, the limits to the emergency exception were addressed. Mrs. Malette, a Jehovah’s Witness, was involved in a car accident and transferred, bleeding and unconscious, to a local emergency room. Despite the discovery of a signed, undated Jehovah’s Witness card refusing consent to blood transfusion, the doctor administered a blood transfusion when it became obvious that transfusion was required to save her life. Subsequently, Mrs. Malette’s daughter arrived at the hospital and confirmed the validity of the wishes contained in the card.
Nevertheless, the doctor administered further blood transfusions. Mrs. Malette survived and sued the doctor for battery. In a unanimous decision, the Ontario Court of Appeal held the doctor liable and assessed $20,000 in damages against him. One of us has argued elsewhere that the Malette decision takes insufficient account of the problem of decision making under circumstances of uncertainty. Interestingly, public opinion is split on this issue. In light of theoretical critiques and the empirical data, we advise caution in codifying in legislation limits to the emergency exception to the requirement to obtain informed consent.

Public attitudes towards advocacy were strongly positive. Although advocacy has been used extensively in psychiatric settings, only recently have legislators proposed mandatory advocacy services for all incapable persons. The only factor that seems to seriously undercut public support for advocacy is the nature of the decision. When the decision changes from a serious one, such as heart surgery, to a less serious one, such as a dental filling, public support for advocacy is halved. It was interesting that even the specter of increased taxes or deficits did not undercut public support for advocacy. By contrast, in a recent poll, Canadians clearly favored reducing the deficit over creating new social programs. Moreover, to decrease the deficit, Canadians also favor cutting spending over increasing taxes (Envirorocks Research Group, unpublished data). We are unaware of any published data on public attitudes towards advocacy. We did not assess whether practical problems in implementation of advocacy services, such as delay of treatment while awaiting the advocate's visit, would decrease public support for advocacy. Moreover, the views of patients in the midst of illness may be different from the opinion of healthy members of the public. Future studies should explore these factors.

This study is limited in several ways. First, the questions regarding attitudes may have been affected by social desirability bias whereby respondents give answers they may not believe but think the interviewer wants to hear. Second, questions regarding past behaviors such as advance discussions or directives may have been affected by recall bias. Third, the bivariate associations were not defined a priori and require confirmation in future studies. Fourth, telephone opinion polls do not reach that small segment of the population that has no telephone. Fifth, as noted above, persons who are actually in the hypothetical situations described in some of the questions may have very different opinions from healthy members of the public. Sixth, the number of refusals introduces non-response bias. Because we do not have information about non-respondents, we cannot estimate the impact of this bias. However, our refusal rate is typical of telephone polls in Ontario (Envirorocks Research Group, personal communication), and the validity of telephone polls has been established in other contexts (for example, polling conducted before general elections accurately predicts popular vote). Seventh, although the concepts examined are generalizable to other jurisdictions, the opinions of Ontarians may not be generalizable to other provinces or countries. Finally, our empirical results do not lead to any normative conclusions (the naturalistic fallacy); they merely highlight normative premises such as legislative provisions and regulations that merit reconsideration and/or target areas for public education programs. This is the limitation of public opinion in shaping the law.

A committee of the Ontario Legislature is currently conducting public hearings on the proposed legislation. We have presented these data to the Committee to assist them in amending the proposed legislation. Our experience highlights the potential utility of empirical research in the legislative process.

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