

Nurses' Knowledge, Experiences, and Attitudes Concerning Living Wills

**Barbara Downe-Wamboldt, Lorna Butler,
and Stephen Coughlan**

Une enquête a été menée auprès de 974 infirmières accréditées de la Nouvelle-Écosse, choisies selon un échantillonnage aléatoire, au cours de l'année d'accréditation 1995-96, afin de cerner les éléments suivants relativement aux testaments biologiques: le degré de compréhension manifesté par les infirmières concernant la législation à ce sujet; les expériences qu'elles ont eues, les rôles qu'elles ont joués et les attitudes qu'elles ont exprimées à cet égard; enfin, les obstacles qui, à leurs yeux, les empêchent d'avoir recours aux testaments biologiques dans l'exercice de leurs fonctions, de même que les ressources qui les y encouragent. Les réponses faites par 157 infirmières indiquent qu'elles connaissaient mal la loi sur le consentement médical, la loi sur les hôpitaux et la loi sur les procurations. Bien qu'elles révèlent une attitude positive à l'égard des testaments biologiques et désignent les infirmières comme étant les professionnelles de la santé aptes à aborder cette question avec les patients, peu d'entre elles ont effectivement joué ce rôle. Les répondantes ont évalué leur compréhension des testaments biologiques comme étant faible, et plusieurs ont indiqué qu'elles se sentaient mal à l'aise d'en discuter avec leurs clients. L'infirmière et le milieu de travail sont considérés par les répondantes comme des obstacles à l'utilisation des testaments biologiques; les commentaires révèlent de manière claire que des stratégies pédagogiques et interdisciplinaires devront être employées afin que les infirmières aient plus aisément recours aux testaments biologiques dans l'exercice de leur profession.

A random sample of 974 registered nurses in Nova Scotia were surveyed during the 1995-96 registration year to determine their understanding of living wills legislation; their experiences, roles, and attitudes related to living wills; and their perceptions of the barriers to and resources for using living wills in their practice. Responses from 157 nurses indicated that they were unfamiliar with the Medical Consent Act, the Hospitals Act, and the Powers of Attorney Act. Although they revealed that they had a positive attitude towards living wills, and they identified nurses as the appropriate health professional to initiate discussions about living wills with patients, very few had any actual experience in this role. Respondents rated their understanding of living wills as low, and many indicated that they were uncomfortable discussing the topic with clients. Respondents saw both the individual nurse and the practice environment as barriers to the use of living wills, and they clearly indicated the need for interdisciplinary educational strategies to facilitate the use of living wills in their nursing practice.

Barbara Downe-Wamboldt, Ph.D., R.N., is Associate Professor, School of Nursing, Dalhousie University, Halifax, Nova Scotia. Lorna Butler, Ph.D., R.N., is Clinical Scientist, Nursing Research, Queen Elizabeth II Health Sciences Centre, Halifax. Stephen Coughlan, L.L.B., Ph.D., is associated with the Faculty of Law, Dalhousie University, Halifax.

The role of patients as responsible, autonomous decision-makers in determining their own health care has been the subject of much attention in the literature, specifically the literature on life-sustaining treatment and do-not-resuscitate orders (Fried, Stein, O'Sullivan, Brock, & Novack, 1993; Genuis, Genuis, & Chang, 1994; Law Reform Commission of Canada, 1983; Rasooly et al., 1994; Sabatino, 1993; Zimbelman, 1994). In the United States, the Patient Self Determination Act (PSDA) has shifted the burden to ensure that the public is informed of its rights, particularly in determining future health care, to the health-care agency (Haisfield et al., 1994; Rein et al., 1996). The Canadian Medical Association and the Canadian Nurses Association support the right of individuals to accept or refuse life-saving or life-sustaining treatment, which may be acknowledged by an advanced directive, or living will; however, living wills have not always been honoured (Canadian Medical Association, 1992; Canadian Nurses Association, 1994).

Nurses and other health-care professionals need to be cognizant of current legislation regarding living wills, as well as policies concerning their use within agencies, to ensure that the client's right to choose is upheld. Although living wills have been publicly endorsed and advocated by consumer groups, very little is known about their actual use and many people still are not aware of their rights regarding health-care decision-making (Canadian Pensioners Concerned, 1995). The purpose of this study was to identify and describe registered nurses' awareness and understanding of legislation on substitute decision-makers and living wills; their experiences, roles, and attitudes concerning these issues; and their perspectives on the barriers to and resources for using living wills.

Literature Review

To make decisions about their future health care, people need to understand the meaning of *living will* and *designated proxy*. Previous studies have found a high degree of uncertainty about the concept of a living will and a lack of understanding, even when information has been provided, especially at a time of crisis (Gamble, McDonald, & Lichstein, 1991; Rein et al., 1996; Singer & Lowy, 1991). Patients' decisions to accept or reject a living will are reportedly influenced by their level of understanding, the need to maintain control over treatment decision-making, type of illness, family relationships that might result in burdening or conflict, and perceived authority of health professionals in making treatment decisions (Rein et al.).

The Nova Scotia Hospitals Act (1989) permits the next of kin of an incompetent person to consent to medical treatment on behalf of that person. This Act applies only when the person is being treated in a hospital.

In 1988, Nova Scotia became the first Canadian province to grant individuals some control over their medical care once they have become incompetent. The Medical Consent Act (1989) allows a competent adult to appoint another person to make health-care decisions when he or she is no longer competent: the decision need not automatically fall to the next of kin. This type of living will, usually referred to as a *proxy directive*, does not allow the person to indicate in advance that they would accept or refuse particular types of treatment, or to express other wishes with regard to medical care.

Since that time, some court decisions in Ontario have held that the clearly expressed wishes of a competent person must be respected, even if the person is no longer in a position to make decisions (Fleming v. Reid & Gallagher, 1991; Malette v. Shulman, 1990). As of January 1998, Manitoba, Newfoundland, Ontario, Quebec, and the Yukon have introduced legislation concerning living wills or a substitute decision-maker, while Alberta, British Columbia, and Prince Edward Island have passed new laws but have not yet proclaimed them in force. Each of these Acts goes beyond the proxy directives allowed in Nova Scotia, and in addition permits a person to express binding wishes with regard to treatment. This latter type of living will is usually referred to as an *instructional directive*.

Although instructional directives are not legally binding in Nova Scotia, this does not mean that health-care professionals cannot choose to follow them. Some groups have therefore tried to promote their use. The Law Reform Commission of Nova Scotia (1995) has conducted public consultations on living wills and has recommended that the legislation be amended to provide for instructional directives.

Nurses have been described as playing various roles in relation to living wills (such as educator, advocate, and facilitator for patients and families), yet no research has been carried out to describe these roles (Haisfield et al., 1994). Health professionals are responsible for ensuring that treatment choices are consistent with a patient's social, political, and spiritual values, even if these values conflict with those of the care provider (Higgins, 1993). Although both physicians and nurses support the use of living wills, in practice many ignore the instructions they provide (Molloy, Harrison, Farrugia, & Cunje, 1993).

There is a paucity of literature exploring nurses' knowledge, experience, and attitudes concerning living wills. The specific needs of nurses in various health-care settings to initiate and implement living wills requires further investigation.

Method

Design

This exploratory, descriptive study used a 12-page survey questionnaire consisting of true-false, yes-no, and Likert-scale items as well as open-ended questions. The questionnaire was developed by the researchers based on the current literature, and included 9 items from the Medical Consent Act Survey (Elgie, MacIntosh, & Rideout, 1992). It was designed to determine nurses' awareness of current provincial legislation; knowledge, experiences, roles, and attitudes concerning living wills; perceptions of barriers to the use of living wills; and resources to facilitate use of living wills in nursing practice. The instrument was assessed for content validity and clarity by a multidisciplinary panel of experts (lawyer, nurse, social worker) external to the research team.

Sample

Subsequent to obtaining approval from the appropriate institutional ethical review boards, a random sample of 974 nurses was identified using the registration list of the Registered Nurses Association of Nova Scotia (RNANS). Sample size was determined on the basis of a 95% confidence interval, a 5% (± 0.05) margin of error, and an expected response rate of 50%. The questionnaire, a letter describing the purpose of the study, and a stamped return envelope were mailed to the sample. A total of 157 nurses returned the completed questionnaire, yielding a response rate of 16%. The nurses who participated in the study were representative of the RNANS membership with respect to gender, age, and number of years elapsed since completion of initial nursing education (RNANS, 1996) (Table 1). Most were female ($n = 144$, 92%), the mean age was 41 years, and they had completed their initial nursing education an average of 19 years previously. The majority of respondents reported a higher level of nursing education than that for the RNANS general membership; 49% were prepared at the diploma level, differing significantly from the general membership ($\chi^2 = 84.1$, $p = 0.001$, $df = 1$) (Table 1).

The most frequently identified practice settings were tertiary hospital (24%), regional hospital (18%), and community hospital (17%).

Table 1 *Characteristics of Registered Nurses in Nova Scotia and of Sample*

Risk Status	Nova Scotia N = 9,260	Sample N = 157
	<i>P</i>	<i>P</i>
Gender		
Female	98	92
Male	2	8
Nursing education		
Diploma	80	49
Baccalaureate	20	51
Continuing education		
Nursing	22	22
Other	11	8
	<i>M</i>	<i>M</i>
Average age	41	41
Average number of years since graduation	18	19

Most respondents worked in rural Nova Scotia ($n = 104$, 66%) and were on staff as casual employees ($n = 92$, 58%). Within the practice setting, the nurses reported that they had little experience in the previous 5 years in attending educational sessions on living wills ($n = 131$, 83%) or participating on committees to address the use of living wills ($n = 143$, 91%).

Data Analysis

Descriptive statistics were used to identify the mean, standard deviations and percentage of scores for responses to the close-ended items. The chi-square statistic was used to compare the characteristics of the sample and the population. Content analysis was used to categorize the narrative data from the open-ended questions. Categories were created by comparative analyses and synthesis of the responses with the relevant literature. Inter-rater reliability of the final category system was assessed through independent coding of a random selection of 56 units of analysis, resulting in a 95% agreement level. Because the sample was more highly educated than the population, Fisher's exact test and Student's t test were used to determine whether there were group differences, based on education, in knowledge, experience, and attitudes.

Findings

Knowledge

Nurses were asked if they were aware of options for people in Nova Scotia to use living wills. Using a Likert scale (1 = very aware, 10 = not at all aware), respondents rated themselves ($M = 7.4$, $SD = 2.62$) as not aware of the options. When questioned about specific Nova Scotia legislation affecting some aspects of living wills, the majority of respondents indicated that they were not familiar with the Medical Consent Act (1989) ($n = 103$), the Hospitals Act (1989) ($n = 118$), or the Powers of Attorney Act (1989) ($n = 95$). However, 133 of the nurses knew the meaning of *durable power of attorney* (DPA) for health care and knew that an instructional directive provides instruction for the kinds of treatment a person wishes to receive ($n = 69$).

Forty respondents identified (correctly) that a designated proxy is legally recognized in Nova Scotia. Many respondents ($n = 69$) knew that under the Medical Consent Act (1989) a person could designate an individual to make decisions about their medical care. Sixty-four respondents knew that under the Medical Consent Act any competent person could write a living will and that under the Hospitals Act (1989) a patient's spouse was legally designated next-of-kin for the purpose of consent to treatment ($n = 50$).

Fifty-two respondents believed (incorrectly) that it was the Hospitals Act (1989) that allowed a person to designate an individual to make decisions about their medical care. Fifty-six respondents thought that under the Hospitals Act any competent person could write a living will. Many ($n = 50$) believed (incorrectly) that the Medical Consent Act (1989) rendered a patient's spouse a legally designated next-of-kin for the purpose of consent to treatment. Several respondents believed (incorrectly) that people could indicate the forms of treatment to be accepted or refused if they became incompetent under the Medical Consent Act ($n = 66$) and under the Hospitals Act ($n = 55$). The majority of respondents ($n = 128$) believed (incorrectly) that the living will should be followed in a situation in which a designated proxy for an incompetent patient disagreed with the living will.

To identify a profile of the most knowledgeable respondents, Student's t tests and Fisher's exact test were used to compare nurses prepared at the diploma level to those who had received higher nursing education. No statistically significant differences were found between the two groups for awareness of legislation. Diploma-prepared nurses

were more knowledgeable about the extent to which a designated proxy could express an individual's preference for care ($t = -2.51$, $p = 0.013$). When respondents were asked if living wills provided instruction only for the kinds of treatment a person wished to receive, Fisher's exact test indicated that a diploma education was more strongly associated with the correct response for both instructional directive ($p = 0.028$) and designated proxy ($p = 0.021$).

Experience

The majority of nurses indicated that they had no experience with using either instructional directives ($n = 113$) or designated proxies ($n = 120$). No statistically significant differences in experience based on education were found. The 37 respondents who reported experience with living wills indicated that the majority of their patients were 65 years of age or over. Using a checklist, these nurses identified their role in discussions related to living wills as advocate ($n = 28$), combination of roles ($n = 11$), facilitator ($n = 5$), and educator ($n = 2$). Narrative descriptions of experiences with living wills from 9 participants reflected the roles of educator ($n = 6$), advocate ($n = 3$), caregiver who follows the patient's wishes ($n = 2$), and provider of support ($n = 1$). These roles were reflected in the following comment: "I helped to get information to family and listened to clients express their desires on how they wished to be treated if and when hospitalization was needed." Five respondents indicated that they did not believe they had a role in relation to living wills: "Not my place, private matter." One respondent stated, "We were not permitted to follow the terms of her living will as her doctor would not honour it."

Attitudes

Nurses reported that living wills were very helpful (1 = very helpful, 10 = not at all helpful) in their nursing care, identifying an instructional directive ($M = 2.7$, $SD = 2.5$) as slightly more helpful than a designated proxy ($M = 3.02$, $SD = 2.7$). Responses on a 10-point Likert scale indicated that both instructional directives and designated proxies helped nurses to plan care, helped patients to express their preferences for care, promoted effective communication between patients and health-care providers, and benefited family members by relieving them of difficult decision-making (Table 2). Respondents strongly disagreed (1 = agree strongly, 10 = disagree strongly) that living wills restricted their nursing practice (instructional directive, $M = 9.2$, $SD = 1.9$; designated proxy, M

= 9.1, $D = 1.9$) or altered the quality of the nursing care they provided to a patient (instructional directive, $M = 9.1$, $SD = 2.4$; designated proxy, $M = 9.1$, $SD = 2.3$). Respondents agreed (1 = totally agree, 10 = totally disagree) with the statement that nurses should promote the use of instructional directives ($M = 3.3$, $SD = 2.8$) and designated proxies ($M = 3.3$, $SD = 2.9$) with all of their patients.

Table 2 *Nurses' Attitudes Towards Living Wills*

Attitude	Instructional Directive		Designated Proxy	
	M^*	SD	M^*	SD
Help nurses plan care	2.5	2.3	2.7	2.4
Help patients express wishes	1.7	1.5	1.8	1.5
Promote communication between patients and health professionals	2.5	2.1	2.5	2.0
Benefit family members	2.2	2.0	2.5	2.3
* 1 = very helpful, 10 = not at all helpful				

Few differences in attitudes were found between diploma and more highly educated nurses. The belief that a designated proxy was helpful in planning patient care was greater among diploma-educated nurses ($t = -2.01$, $p = 0.05$). Using Fisher's exact test, the belief that information on living wills should be offered to persons newly diagnosed with a life-threatening illness ($p = 0.02$) or persons with a terminal illness ($p = 0.05$) was found to be more closely associated with a diploma education.

Although most ($n = 53$) of the respondents' narrative comments indicated that they had no experience with living wills, comments from those who did have experience ($n = 19$) reflected a positive attitude towards their use. Benefits ($n = 7$) were described for family, patients, and nurses: "I found a living will very beneficial to the care of my patients"; "Easier to deal with the family, patient more at ease"; "being aware of patient's and family's wishes makes nursing that person much easier." Two responses indicated that living wills had no effect on patient care: "Care remains the same for all patients"; "The living will did not alter the care given to the patient." Only one response reflected a negative experience with living wills: "It is not easy, especially if you don't agree with the decision."

A total of 29 respondents identified potential benefits of living wills for family and patients, as well as for nursing care. The following comments provide vivid examples of the perceived benefits for families and patients: "Opens communication"; "Family members can benefit because when a family member is very ill he may not express his desire to die because his family is doing everything to keep him alive, many families avoid the issue of death"; "Patients can be dealt with honestly and time allowed to share and express concerns, problems etc. in preparation for death." The following comments indicate that living wills provide direction for nursing care: "It would stand to reason that for us and for family to know a patient's wishes would be helpful"; "I believe living wills would be most helpful in care planning, decision making, and would not lower level of care"; "In our setting, nursing home, it would help us to know how aggressively the clients are to be treated or not." One response indicated a negative effect on family: "Opportunity for conflict exists if family members oppose the choices of the patient and proxy, for example if the proxy is not liked by the family."

Barriers

Using a 10-point Likert scale, the nurses clearly identified lack of knowledge, legal concerns, lack of agency support, and ethical concerns as perceived barriers to the use of living wills in their practice (Table 3). They identified that they were not effective (1 = not effective, 10 = most effective) in implementing either instructional directives ($M = 3.6$, $SD = 3.0$) or designated proxies ($M = 3.5$, $SD = 2.9$). Many nurses ($n = 55$) indicated that they were uncomfortable raising or discussing the topic of living wills, and 57 believed that patients and families were also uncomfortable with the topic. Interestingly, only 7 nurses thought it was the responsibility of the physician or some other health professional ($n = 5$) to discuss living wills with patients or families.

Table 3 *Barriers to Use of Living Wills in Practice*

Attitude	Instructional Directive		Designated Proxy	
	<i>M*</i>	<i>SD</i>	<i>M*</i>	<i>SD</i>
Lack of knowledge	1.9	2.0	2.0	2.0
Legal concerns	3.1	2.0	3.2	2.9
Lack of agency support	3.2	2.7	3.2	2.9
Ethical concerns	4.8	3.4	4.5	3.4

* 1 = very helpful, 10 = not at all helpful

Resources

Respondents' written comments ($n = 157$) identified resources that would help their practice regarding living wills. The resources identified most frequently were lawyers (29.95%), continuing education on living wills (12.83%), development of agency policies (11.76%), relevant literature such as found in professional journals (10.16%), social workers (8.02%), clergy (7.49%), and hospice and/or palliative-care staff (7.49%). Other resources (12.30%) identified included family members, patients, physicians, and an interdisciplinary-team approach to practice.

Table 4 *Perceived Helpfulness Ratings of Educational Topics*

Strategy	<i>n</i>	<i>M</i>	<i>SD</i>
Discussions of types of living will	142	9.4	1.54
Discussions of legal issues			
Instructional directive	144	9.3	1.60
Designated proxy	142	9.3	1.60
How to implement a living will			
Instructional directive	143	9.2	1.60
Designated proxy	140	9.3	1.50
How to facilitate the use of living wills			
Instructional directive	144	9.3	1.60
Designated proxy	142	9.3	1.60
Discussions of ethical issues			
Instructional directive	143	9.1	1.80
Designated proxy	140	9.1	1.80
How to write a living will			
Instructional directive	141	8.8	2.20
Designated proxy	138	8.8	2.10
Communication strategies with patients			
Instructional directive	144	8.7	4.70
Designated proxy	142	8.3	2.60
Communication strategies with families			
Instructional directive	143	8.5	2.50
Designated proxy	141	8.5	2.50

Nurses were asked to rate on a Likert scale (1 = not helpful, 10 = extremely helpful) each of 8 educational topics that could address issues related to living wills (Table 4). The mean scores, which ranged from 8.3 to 9.4, suggested that all of the topics were perceived as relevant. When asked to identify the ideal instructor for specific educational sessions, from a list of 9 options, respondents most frequently chose nurses, lawyers, physicians, clergy, social workers, and hospice staff (Table 5).

Discussion

Of the 974 questionnaires mailed out, only 157 (16%) were returned. This unusually low response rate is itself significant. It may be that many nurses were unwilling to participate because of lack of familiarity with the issues. The respondents, who had a higher level of nursing education than the typical registered nurse in Nova Scotia, rated themselves as unaware of the options in Nova Scotia for using living wills, and the majority described themselves as unfamiliar with the Medical Consent Act (1989), the Hospitals Act (1989), and the Powers of Attorney Act (1989). Very few differences were found in participants' responses based on education, which means that a relatively small percentage of nurses are familiar with these Acts. These results are similar to those of an earlier, unpublished study with physicians (Elgie et al., 1992). The low response rate of the present study, and the sample profile in terms of education, limits the generalizability of the results.

It is possible that nurses under-reported their familiarity with issues surrounding living wills. Although only 54 respondents indicated that they were familiar with the Medical Consent Act (1989), 133 indicated that they knew the meaning of DPA for health care. Similarly, over half the respondents answered many of the specific questions about instructional directives and designated proxies. This could be interpreted to mean that many nurses were aware of the issues but were unfamiliar with the specific legislation and were uncomfortable with the language. Supporting this interpretation are the answers found in the knowledge section of the questionnaire. Generally, respondents' answers regarding the options available to patients were correct: 89% knew that any competent person could write a living will, 96% knew that under the Medical Consent Act one person could designate another to make decisions for them, and 71% knew that under the Hospitals Act (1989) a spouse was legally designated next-of-kin for the purpose of consent to treatment.

The respondents were generally mistaken in their understanding of instructional directives: 63% believed that this form of living will was recognized under Nova Scotia law. In similar findings, Elgie et al. (1992) reported that 95.2% of physicians in Nova Scotia believed, incorrectly, that a living will could be written under the authority of the Medical Consent Act (1989). The present study found that 85% of nurses thought the instructions in a directive should be followed even if the designated proxy disagreed with them. However, designated proxies were in fact recognized under Nova Scotia law and instructional directives were not.

The likely explanation is that respondents relied on their experience with or knowledge of do-not-resuscitate orders, commonly called DNRs, or no-codes. Although not actually legally recognized, DNRs are a type of instructional directive in one particular situation, and are in common use in hospitals across the country. Many comments from nurses indicated that their experience had been with DNRs. Further supporting this interpretation are some agency policies reported by respondents; for example, 99 nurses indicated that a special form was required for a designated proxy and an instructional directive ($n = 104$). Although no special form is legally required for a designated proxy, hospitals do typically have rules for how DNRs are to be entered in a patient's chart.

The results reveal interesting contrasts between reported attitudes and reported practice. The respondents consistently indicated that the nurse was the most appropriate person to deal with living wills, whether this involved communicating with patients, communicating with families, or facilitating the use of and implementing living wills. Yet very few reported fulfilling any of these functions. Similarly, respondents reported a very positive attitude towards the principle of living wills. They thought living wills were helpful in planning patient care, promoted effective communication, and benefited family members. Virtually all comments on living wills were positive, indicating that nurses should promote their use and support policies in that direction. Yet respondents acknowledged that they were not acting on these beliefs.

The nurses rated their understanding of living wills as low. More significantly, many reported that they either were uncomfortable raising the topic or felt that patients and families would be uncomfortable with it. They believed that promoting living wills was an important part of their function, yet they were reluctant to play this role. This reluctance might be justified by the fact that it would be hard for nurses to assume this role without a greater understanding of the legal and ethical issues it entails.

Conclusion

A very high percentage of respondents had a positive opinion of living wills, whether or not they had experience using them. Nurses perceived living wills as valuable for them, the patient, and the family. Nonetheless, a high percentage expressed a lack of knowledge about and some discomfort with the issue of living wills. The nurses acknowl-

edged that they were not promoting the use of living wills. This has been a consistent finding in Canada (Molloy et al., 1993).

Strategies to facilitate the use of living wills must focus on the individual nurse, the context of practice, and public awareness. To the extent that lack of information plays a role, steps can be taken. Table 4 describes the educational topics that nurses identified as potentially helpful in facilitating their practice. The central point to emerge from this table is that all of the listed strategies were identified as potentially helpful by a large majority of respondents. Further, Table 5 clearly indicates that an interdisciplinary model of education would address the issues that nurses perceive as relevant to their work. In addition, as recommended by Elgie et al. (1992), hospitals and other health-care agencies should be encouraged to develop policies concerning living wills, with a view to educating both health professionals and the general public.

Future research should examine the effectiveness of various interdisciplinary educational strategies in facilitating nursing practice in the area of living wills. The present study found that many nurses are uncomfortable discussing living wills with patients, families, and other health professionals. Further research could explore the effectiveness of collaborative models of communication among agencies and disciplines on the use of living wills.

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Requests for reprints should be addressed to: School of Nursing, Dalhousie University, Halifax, NS B3H 3J5; tel.: 902-494-2535; fax: 902-494-3487.