Advance directives

Survey of primary care patients

Rory O'Sullivan MD CCFP(EM) Kevin Mailo MD CCFP(EM) Ricardo Angeles MD MPH MHPEd PhD Gina Agarwal MBBS MRCGP CCFP PhD

Abstract

Objective To establish the prevalence of patients with advance directives in a family practice, and to describe patients' perspectives on a family doctor's role in initiating discussions about advance directives.

Design A self-administered patient questionnaire.

Setting A busy urban family medicine teaching clinic in Hamilton, Ont.

Participants A convenience sample of adult patients attending the clinic over the course of a typical business week.

Main outcome measures The prevalence of advance directives in the patient population was determined, and the patients' expectations regarding the role of their family doctors were elucidated.

Results The survey population consisted of 800 participants (a response rate of 72.5%) well distributed across age groups; 19.7% had written advance directives and 43.8% had previously discussed the topic of advance directives, but only 4.3% of these discussions had occurred with family doctors. In 5.7% of cases, a family physician had raised the issue; 72.3% of respondents believed patients should initiate the discussion. Patients who considered advance directives extremely important were significantly more likely to want their family doctors to start the conversation (odds ratio 3.98; $P<.05$).

Conclusion Advance directives were not routinely addressed in the family practice. Most patients preferred to initiate the discussion of advance directives. However, patients who considered the subject extremely important wanted their family doctors to initiate the discussion.

EDITOR'S KEY POINTS

- Formal advance directives protect patient autonomy and reduce the use of health care resources, but most patients do not hold them. Previous studies have suggested that patients might prefer to discuss advance directives in an outpatient setting, and might prefer that their primary care doctors initiate the discussion.

- Patients with advance directives were not prevalent (19.7%) in this study. Most of the patients surveyed would prefer to initiate the discussion of advance directives themselves. The preference to have a family doctor initiate the discussion correlated strongly with patients' higher ranking of the importance of advance directives.

- Discussions of advance directives are happening more widely than anticipated (43.8%), although they occur largely outside the purview of the family doctor—usually with family or friends, or with a lawyer.

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Advance directives are widely considered to be essential tools in protecting patient autonomy, particularly at the end of life. The term *advance directive* has multiple definitions in the literature, but a reasonable working definition is "a person's oral and written instructions about his or her future medical care, in the event he or she becomes unable to communicate."[1] In some jurisdictions, this is referred to as an *advance care plan* or a *living will*. Although they might be applicable in any clinical scenario, advance directives are typically invoked in situations of terminal illness and end-of-life care. In an age of sophisticated management of critical illness, and in the face of an aging population,[2] advance directives have substantial implications for effective patient care and for use of health care resources.

Despite their increasing importance, advance directives remain an apparently underused tool. Various population estimates from the United States suggest that the proportion of adults who hold advance directives is between 5% and 25%, although this might increase with age and hospitalization.[3,4] A 1993 survey of 304 Canadian outpatients by Sam and Singer found that no participants held advance directives.[5] In our own Canadian urban practice, an unpublished chart review of 142 randomly selected patients in 2009 established that 8 patients had documentation of their wishes at the end of life. Public awareness and tools for the development of advance directives were identified as priorities by the Quality End-of-Life Care Coalition of Canada in their 2010 *Blueprint for Action*.[6]

The primary care office visit is a potentially useful setting for advance care discussions. Past studies have established that many patients would prefer to hold these discussions in the outpatient setting,[7] and many would prefer that their primary care doctors initiate the discussion.[5,8,9] To date, many of the studies regarding advance directives in primary care have been small, retrospective in nature, or limited to elderly or palliative care populations.

Our study aimed to establish the prevalence of advance directives in our patient population, and to elucidate our patients' expectations regarding the role of their family doctors.

METHODS

This was a cross-sectional analytical study. A voluntary, anonymous, self-administered questionnaire was developed, informed by review of relevant literature and by the authors' clinical experience. Ethics approval was obtained from the Hamilton Health Sciences–Faculty of Health Sciences Research Ethics Board. The survey was offered to each adult patient (aged 18 years or older) who attended our (at the time of the study, R.O., K.M., and J.A.) urban family medicine teaching clinic during the course of a typical business week in November 2011.

Data were compiled and analyzed initially using descriptive and nonparametric statistics. Logistic regression was used to determine factors associated with the likelihood of patient preference in having family doctors initiate discussions regarding advance directives.

RESULTS

A total of 1104 patients attended our clinic during the selected week (mean age 53 years), of whom 800 completed the survey (a response rate of 72.5%). The participants' demographic characteristics are shown in **Table 1**. Most of the participants were women (61.0%). There was a broad age distribution except for a low number of participants aged 80 years and older, which probably represents the actual population distribution of clinic patients.

Table 1. Patient demographic characteristics: *N* = *800.*

VARIABLE	N (%)*
Sex	
• Male	312 (39.0)
• Female	488 (61.0)
Age, y	
• 18-34	191 (23.9)
• 35-49	234 (29.3)
• 50-64	188 (23.5)
• 65-79	147 (18.4)
• ≥ 80	40 (5.0)

*Some values do not add to 100% owing to rounding.

Of the 800 participants, 19.7% had written advance directives and 43.8% had previously discussed advance directives. Of the total population, 16.2% reported that they had recently undergone an important surgery or hospitalization. Patients had most commonly discussed the issue with family and friends (39.5%), followed by with their lawyers (10.9%), in the context of important surgery (6.8%), in the context of an important hospital stay (4.9%), with their family doctors (4.3%), or in another setting (3.1%) (**Table 2**). Other settings included after the birth of a child, with a midwife, with a funeral director, and with clergy or a spiritual leader.

Overall, 21.4% of the survey population rated advance directives as not important, 37.9% as somewhat important, 26.0% as quite important, and 14.7% as extremely important. Family physicians had raised this issue with 5.7% of the patients. When asked who should raise the subject of advance directives, 72.3% indicated that the patient should, and 28.1% indicated that the family doctor should.

Table 2. Context in which survey respondents discussed advance directives: *N* = 800.

CONTEXT	N (%)
With their family or friends	316 (39.5)
With their lawyers	87 (10.9)
Before an important surgery	54 (6.8)
During an important hospital stay	39 (4.9)
With their family doctors	34 (4.3)
In another setting	25 (3.1)

A logistic regression model was used to determine whether age, sex, or perceived importance of advance directives were associated with the participants' preference to have discussions initiated by themselves or their family doctors. The results showed that age and sex did not affect participant preference. However, participants who perceived advance directives as somewhat, quite, or extremely important were significantly ($P < .05$) more likely to prefer that their family doctors initiate the conversation about advance directives (odds ratios 1.79, 1.74, and 3.98, respectively, using the "not important" group as a reference standard).

DISCUSSION

Patients with advance directives were not prevalent in our study population (19.7%). This is consistent with previous studies across North America. In a 2013 Canadian study of elderly patients and family members, Heyland et al identified that, although 76.3% had thought about end-of-life care and 47.9% had completed an advance care plan, only 30.2% had discussed their wishes with their family doctors.[10] This study focused on an acute-care hospital population at risk of dying. The gap between consideration of advance care and discussion with a family doctor seems to widen in our more general outpatient survey population. The initial phase of the SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) trial in 1995 found that 46% of do-not-resuscitate orders were written within 2 days of death.[11] Literature suggests that the physician-patient relationship is a key element in patient satisfaction at the end of life,[12,13] and at least 1 study found that discussing advance directives in primary care increased global patient satisfaction.[14]

Our study examined patient impressions regarding planning for end-of-life care. It appears that these discussions are happening more widely than we had anticipated (43.8% in our study), although they occur largely outside the purview of the family doctor. It is not routine practice in our clinic to raise the issue with our patients. However, it is also apparent that most patients prefer some control over how and when these issues are approached. As advance directives were rated as more important, having a family doctor initiate the discussion became more desirable. Past studies have found higher rates (up to 62% to 72%) of patients desiring that their physicians initiate the discussion, although the study populations were stratified differently.[5,9,14]

Limitations

We studied a sample of patients attending a busy urban teaching practice during a typical week. This practice population in a small Canadian urban centre is in close proximity to a relatively impoverished inner city, an industrial area, and a large university. Our study includes a social spectrum from inner-city patients of low socioeconomic status, new immigrants, and refugees to university students and associated professionals. Further study might focus on patients with substantial comorbidities and patients who will soon require palliative care for terminal illness. We did not control for issues of competence, cognitive impairment, or literacy, which might have interfered with accurate study completion. It is important to note that those aged 80 and older in our study were less well represented than other groups were. We are also unable to generalize our results to the patient population that does not typically attend the clinic, either because they do not require medical services or because they are institutionalized or require care at home. These are groups that would merit in-depth study in the future.

Conclusion

Our results show that advance directives are not widely discussed with patients in our practice. Most of those surveyed preferred to retain control of the context of this discussion. The preference to have a family doctor initiate the discussion correlated strongly with patients' higher ranking of its importance. Topics for future study might include patient-identified barriers to these discussions, and a correlation of patient perspectives with physician beliefs and expectations. We hope that our study might facilitate the development of frameworks for patient-centred end-of-life discussions in primary care.

Dr O'Sullivan is a practising family physician and emergency physician in Hawkesbury, Ont, and Sioux Lookout, Ont. **Dr Mailo** is a practising emergency physician in Edmonton, Alta. **Dr Angeles** is a researcher at McMaster University in Hamilton, Ont. **Dr Agarwal** is a clinician researcher and Associate Professor of Family Medicine at McMaster University.

Contributors

All authors contributed to the concept and design of the study; data gathering, analysis, and interpretation; and preparing the manuscript for submission.

Competing interests

None declared

Correspondence

Dr Rory O'Sullivan; e-mail **rory.osullivan@medportal.ca**

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