

Awareness of do-not-resuscitate orders

What do patients know and want?

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Abstract

Objective To assess outpatient understanding of and previous experiences with do-not-resuscitate (DNR) orders and to gauge patient preferences with respect to DNR discussions.

Design Cross-sectional, self-administered survey.

Setting Four urban primary care physician offices in Vancouver, BC.

Participants A total of 429 consecutive patients 40 years of age and older presenting for routine primary care between March and May 2009.

Main outcome measures Awareness of, knowledge about, and experiences with DNR decisions; when, where, and with whom patients wished to discuss DNR decisions; and differences in responses by sex, age, and ethnicity, assessed using χ^2 tests of independence.

Results The response rate was 90%, with 386 of 429 patients completing the surveys. Most (84%) respondents had heard of the terms *do not resuscitate* or *DNR*. Eighty-six percent chose family physicians as among the people they most preferred to discuss DNR decisions with; 56% believed that initial DNR discussions should occur while they were healthy; and 46% thought the discussion should take place in the office setting. Of those who were previously aware of DNR orders, 70% had contemplated DNR for their own care, with those older than 60 years more likely to have done so ($P=.02$); however, only 8% of respondents who were aware of DNR orders had ever discussed the subject with a health care provider. Few patients (16%) found this topic stressful.

Conclusion Most respondents were well informed about the meaning of DNR, thought DNR discussions should take place when patients were still healthy, preferred to discuss DNR decisions with family physicians, and did not consider the topic stressful. Yet few respondents reported having had a conversation about DNR decisions with any health care provider. Disparity between patient preferences and experiences suggests that family physicians can and should initiate DNR discussions with younger and healthier patients.

EDITOR'S KEY POINTS

- Not all patients desire cardiopulmonary resuscitation and intubation after suffering cardiopulmonary arrest, and such measures might be medically inappropriate and might cause undue harm to patients, families, and caregivers. Yet physicians are often not aware of their patients' resuscitation preferences.
- The objectives of this study were to determine outpatients' awareness of do-not-resuscitate (DNR) orders and to understand their preferences surrounding where, when, and with whom they preferred to discuss DNR options.
- By far most respondents had heard the terms *do-not-resuscitate* or *DNR*. Among the DNR-aware respondents, 38% had previously dealt with DNR decisions for someone close to them.
- Most respondents (86%), including both DNR-aware and DNR-naïve respondents, identified family physicians as among the people they most preferred discussing DNR decisions with; however, only a few (8%) DNR-aware participants had discussed DNR orders with any health care provider.

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Sensibilisation à l'ordre de ne pas réanimer

Que savent et que veulent les patients?

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Résumé

Objectif Déterminer ce que les patients comprennent aux ordres de « ne pas réanimer » (NPR) et l'expérience qu'ils en ont, et évaluer leurs préférences en ce qui concerne les discussions sur l'ordre NPR.

Type d'étude Enquête transversale auto-administrée.

Contexte Quatre bureaux urbains de médecins de première ligne à Vancouver, C.-B.

Participants Un total de 429 patients consécutifs de 40 ans et plus ayant consulté entre mars et mai 2009 pour des soins de routine.

Principaux paramètres à l'étude Le fait d'être au courant de la consigne NPR, de la connaître et d'en avoir une expérience; quand, où et avec qui les patients voudraient discuter de cette option; et les différences de réponses selon le sexe, l'âge et l'origine ethnique, évaluées dans le cadre de tests d'indépendance de χ^2 .

Résultats Le taux de réponse était de 90%, 386 patients sur 429 ayant répondu à l'enquête. La plupart des répondants (84 %) avaient déjà entendu l'expression ne pas réanimer ou NPR. Parmi ceux avec qui ils pourraient discuter de la décision de NPR, 86 % des patients ont dit préférer le médecin de famille; 56 % croyaient que la discussion initiale sur ce sujet devrait avoir lieu pendant qu'ils sont en santé; et 46 % estimaient que cette discussion devrait avoir lieu au bureau du médecin. Parmi ceux qui étaient déjà au courant de l'ordre NPR, 70 % avaient songé à une telle option pour eux-mêmes, les plus de 60 ans étant les plus susceptibles d'y avoir songé ($P=,02$); toutefois, seulement 8 % de ceux qui connaissaient l'ordre NPR en avaient déjà discuté avec un soignant. Peu de patients (16 %) ont trouvé que ce sujet était stressant.

Conclusion La plupart des répondants connaissaient bien la signification de NPR, pensaient que la discussion à ce sujet devrait avoir lieu quand le patient était encore en santé, préféraient avoir cette discussion avec le médecin de famille et estimaient que ce sujet n'était pas stressant. Pourtant, peu de répondants déclaraient avoir eu une conversation sur la décision de NPR avec un professionnel de la santé. La disparité entre ce que les patients souhaitent et ce qu'ils font donne à penser que le médecin de famille devrait entamer la discussion sur l'ordre de NPR avec des patients plus jeunes et en meilleure santé.

POINTS DE REPÈRE DU RÉDACTEUR

- Ce ne sont pas tous les patients qui désirent être intubés et avoir une réanimation cardiopulmonaire en cas d'arrêt cardio-respiratoire; de plus, une telle intervention pourrait être inappropriée et avoir des conséquences indésirables pour le patient, les familles et les soignants. Pourtant, les médecins ignorent souvent les préférences de leurs patients concernant la réanimation.
- Cette étude avait pour but de déterminer ce que les patients externes connaissent de l'ordre de *ne pas réanimer* (NPR) et d'établir leurs préférences concernant le lieu, le moment et la personne avec qui ils voudraient discuter de cette option.
- La très grande majorité des répondants avaient entendu parler de l'expression *ne pas réanimer* ou NPR. Parmi ces derniers, 38 % avaient déjà été confrontés à une décision de NPR dans le cas d'un proche.
- La plupart des répondants, qu'ils connaissent ou non l'expression NPR, ont dit que le médecin de famille était celui avec qui ils préféraient discuter d'une décision de NPR; toutefois, seulement 8 % des répondants qui connaissaient l'ordre de NPR en avaient déjà discuté avec un professionnel de la santé.

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A do-not-resuscitate (DNR) order is arguably one of the most important decisions in patient care, yet it is an area in which the necessary physician-patient communication is often neglected.¹⁻⁵ Cardiopulmonary resuscitation (CPR) as we know it today was first conceived of in 1960. As declared in *Fundamentals of Cardiopulmonary Resuscitation*, “the physician should concentrate on resuscitating patients who are in good health preceding arrest, and who are likely to resume a normal existence.”⁶ It appears that the interpretation of these principles has since changed. In our current system, patients remain “full code” until designated otherwise. If the topic of DNR has not been addressed with a hospitalized patient, then CPR and further resuscitation efforts are automatically performed when the patient suffers cardiopulmonary arrest. Not all patients desire CPR and intubation, however, and such measures might be medically inappropriate and might cause undue harm to the patients, families, and caregivers. Yet physicians are often unaware of their patients’ resuscitation preferences.^{1,2,4,7-9}

Previous research suggests that patients and families might lack general knowledge about what the term *do not resuscitate* implies, and this confusion can lead to added stress at already difficult times.^{8,10} Often patients and families have an inaccurate understanding of the odds of survival following CPR, with much of their understanding of resuscitation coming from television.^{1,11} When making a DNR decision for a loved one, many surrogate decision makers rely upon their own views rather than patient preferences¹²; however, they will often change their DNR directives after receiving detailed information.¹³⁻¹⁷ A surrogate’s ability to predict a patient’s wishes is only moderately better than chance.¹⁸ This lends further credence to the assertion that patients’ wishes should be explored before patients become ill, and certainly before they become incompetent.

Physicians can only know patient preferences with respect to CPR if discussion about resuscitation has occurred. This discussion must ensure proper understanding of what it would mean to choose the DNR option and must involve an ethical and compassionate exploration of end-of-life wishes.¹⁹ Although physicians are often involved with how their critically ill patients die, it is unclear where and when patients would like DNR conversations to take place or with whom. Improved knowledge about patient preferences will assist caregivers in facilitating these life-and-death discussions, while respecting patient autonomy and decreasing the number of unwanted and unnecessary interventions.

The objectives of this study were to determine outpatients’ awareness of the terms *do not resuscitate* or *DNR* and to determine their preferences regarding when, where, and with whom they wished to have DNR discussions.

METHODS

This study was approved by the University of British Columbia Behavioural Research Ethics Board. A 2-part questionnaire was drafted; reviewed for face and content validity by 7 experienced family physicians, a statistician, and 8 resident physicians; then pilot-tested with 10 family practice office personnel. The questionnaire is available from the authors on request.

The self-administered questionnaire ascertained age, sex, and ethnicity, then asked whether respondents had previously heard the term *do not resuscitate*. Yes or no responses branched to separate survey pages. Respondents who answered yes (ie, who were previously aware of the term) were asked to identify the correct definition from among 4 plausible descriptions, then answer questions about previous DNR experiences. Respondents who answered no (ie, had not heard of the term) were provided with the following definition: “A do-not-resuscitate order means that a person would prefer to die a natural death; ie, if their heart stops beating, they do not wish for medical personnel to try and save them using CPR (cardiopulmonary resuscitation).” All participants were asked about where, when, and with whom they would prefer DNR discussions to take place.

Recruitment occurred in 4 urban primary care physician offices in Vancouver, BC, from March to May 2009. Medical office assistants offered the survey when patients checked in to all those 40 years of age and older presenting for routine medical appointments. Forty was chosen as the age at which a meaningful proportion of patients would have already contemplated their own mortality. To ensure anonymity and independence from provision of care, instructions included the suggestion to return blank surveys to the collection box if patients chose not to participate.

Demographic characteristics were summarized in frequency tables. Reported percentages are valid percents, with nonrespondents excluded from analysis. Responses were compared using cross-tabulations and χ^2 tests of independence, with *P* values of less than .05 considered statistically significant.

RESULTS

The response rate was 90%, with 429 surveys distributed and 386 completed. Demographic characteristics of the participant population are presented in **Table 1**.

Most respondents (84%) had heard the terms *do not resuscitate* or *DNR* (these respondents will be henceforth referred to as *DNR aware*, while their counterparts will be referred to as *DNR naïve*), with no significant differences between men and women (80% vs 86%; *P* = .15) or

Table 1. Participant demographic characteristics:
N = 386.

| CHARACTERISTIC | N (%) |
|-------------------|----------|
| Sex* | |
| • Male | 141 (38) |
| • Female | 233 (62) |
| Age,† y | |
| • 40-49 | 133 (36) |
| • 50-59 | 102 (27) |
| • 60-69 | 68 (18) |
| • 70-79 | 50 (13) |
| • 80-89 | 19 (5) |
| • ≥90 | 3 (1) |
| Ethnicity† | |
| • Aboriginal | 8 (2) |
| • White | 283 (76) |
| • East Asian | 48 (13) |
| • Southeast Asian | 8 (2) |
| • South Asian | 11 (3) |
| • Other | 17 (4) |

*Twelve participants did not respond to this question; nonrespondents were excluded from analysis.

†Eleven participants did not respond to this question; nonrespondents were excluded from analysis.

among age groups ($P=.91$). Eighty-three percent of the DNR-aware respondents identified the correct definition from among the 4 choices.

Among the DNR-aware respondents, 38% had previously been involved with DNR decisions for someone close to them. There was variability in the reported quality of communication between health care providers and respondents during their involvement in those decisions, with 16% rating communication as poor or very poor, 22% rating communication as fair, and 62% rating communication as very good or excellent. Seventy percent had thought about DNR decisions for themselves, with no difference between men and women (64% vs 72%; $P=.16$). Age was a statistically significant factor in whether patients had previously contemplated DNR orders for themselves: only 65% of respondents aged 40 to 59 years compared with 77% aged 60 and older ($P=.02$) had done so.

Among the DNR aware, respondents were most likely to share their resuscitation wishes with their spouses (34%) and other family members (30%); 17% reported having told no one; and only 8% had discussed resuscitation wishes with health care providers. In contrast, 86% of all respondents (87% of DNR-aware and 80% of DNR-naïve patients) identified family physicians as among the people they most preferred to discuss DNR decisions with, followed by family members, selected by 72% of respondents. (Note that participants could

choose more than 1 response to this question.) Almost half (46%) of all respondents chose the physician’s office as their preferred location for DNR discussions, but nearly as many (39%) preferred to have the discussion at home. Of all participants, 11% chose the hospital as their preferred location to have DNR discussions. With respect to the best time to have a discussion about DNR decisions, 56% thought it most appropriate to have a first discussion about DNR orders when a person was still healthy, while 23% thought diagnosis with a serious medical condition should determine the timing of a first discussion. Two percent wished to have the discussion when admitted to hospital.

Most respondents (84%) did not find the topic of DNR decisions stressful. Men and women were equally likely to find the topic stressful ($P=.55$). Age was also not a significant determinant—10% of those aged 40 to 59 years found the topic stressful compared with 17% of those 60 years of age or older ($P=.10$).

DISCUSSION

This survey was well received by family practice patients, and the high response rate (90%) might be indicative of the importance of the topic. Previous studies looking at CPR found that many patients were aware of CPR,^{4,10} but few accurately understood the term.^{4,20} In our survey, most participants had heard the terms *do not resuscitate* or *DNR* (84%) and were able to identify the correct definition (83% of DNR-aware participants). Our findings might be indicative of improved knowledge and understanding of resuscitation among patient populations.

In this study most respondents (86%), both DNR aware and DNR naïve, identified family physicians as among the people they most preferred to talk to about DNR orders with; however, only a small proportion (8%) of DNR-aware participants had discussed the subject with a health care provider. This large gap between patient preference and action is supported by previous research.¹⁸ Our study lends support to the assertion that patients want to discuss their resuscitation wishes with their physicians.^{3,4,21-24}

Most respondents in our study indicated that the most appropriate time for the first discussion of DNR orders is when a person is healthy. This finding is also supported by other research.^{1,4,25} Despite this, clinical experience and past literature indicate that many DNR discussions occur late in a patient’s course of illness, often in a crisis setting or when the patient is no longer competent.^{2,25,26} Barriers to resuscitation discussions might include the physician’s level of comfort, training prior to the focus on patient autonomy, and practice located away from an academic setting.^{2,23,24} There might also be fear on the physician’s part that introducing a DNR discussion will cause patient distress²⁴; however, our study indicates

this fear might be unfounded, as most participants (84%) did not find this topic stressful. There is even some evidence that such a discussion might improve the mental well-being of patients.^{10,27} Our study indicates that patients wish to discuss DNR directives when they are healthy.

Results of previous studies exploring appropriate settings for DNR discussions lack congruity. One study found that patients preferred the outpatient setting owing to privacy concerns,⁷ while another suggested that patients might prefer the inpatient setting.²³ In our study, a good number of respondents preferred to discuss DNR in an office or home setting, while only a few wished to have this discussion in hospital. Despite this, the hospital still appears to be the most likely location for first-time DNR discussions.

The large disparity between patient experiences and preferences for DNR discussion revealed in our study implies this is an important area of patient care that is not being adequately addressed.

Limitations

Our survey instrument underwent limited validation. That a high number of respondents accurately identified the correct definition of DNR might be a reflection of how the question was asked, rather than a reflection of patient knowledge, and results might have been contaminated by the inclusion of the correct definition on a separate page in the survey (accessible to all participants but intended for the DNR-naïve respondents). This survey was administered in family physicians' offices, which might have biased respondents' choice of person they most preferred to discuss DNR orders with. The study was relatively small, and findings might not be generalizable to rural, suburban, or other populations. Religion and education were not explored in this study and might play important roles in patients' attitudes toward this subject.

Conclusion

A large percentage of the outpatients surveyed were aware of the terms *do not resuscitate* or *DNR*, and wished to have DNR discussions with their family physicians while they were still healthy. Postponement of DNR conversations until patients are admitted to hospital, elderly, or medically frail is not in concert with most patients' wishes. The apparent discrepancy between patient preference and experience suggests that family physicians could and should initiate DNR discussions with younger and healthier patients. In order to help physicians develop confidence in their approach to DNR discussions, more emphasis needs to be placed on this topic during family medicine residency training and in continuing medical education curricula for practising physicians.

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Contributors

Drs Robinson, Kolesar, Boyko, Berkowitz, Calam, and Collins all contributed to the concept and design of the study; data gathering, analysis, and interpretation; and preparing the manuscript for submission.

Competing interests

None declared

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