Central European Journal of
Nursing and Midwifery

Cent Eur J Nurs Midw 2018;9(4):932–938
doi: 10.15452/CEJNM.2018.09.0026

ORIGINAL PAPER

END-OF-LIFE PREFERENCES OF CARDIAC PATIENTS

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Received May 22, 2018; Accepted October 1, 2018.

Abstract

Aim: To address the wishes of patients with cardiovascular disease in relation to their end-of-life stage – an issue that has long been regarded taboo. *Design:* Cross-sectional study. *Methods:* After an initial interview, 127 patients completed an anonymous questionnaire: 86 patients (67.7%) hospitalized in a cardiology department, and 41 patients (32.3%) on follow-up at an outpatient clinic. The mean age was 67 ± 13 years; 60.6% were male; 51.7% were NYHA class III. Seventeen patients (13.4%) had an implantable cardioverter-defibrillator. *Results:* The patients most concerned about their future were those aged 65–79 years ($p = 0.044$); patients who felt they were not receiving sufficient information ($p = 0.008$); hospitalized patients ($p < 0.001$); or those with a known diagnosis of less than one month, or over one year ($p = 0.038$). Seventy-one patients (57.7%) would prefer to die at home, although this would mean receiving less health care than in hospital. Only 19 patients (15.4%) expressed a preference for extension of life over quality of life. Twenty-nine patients (23.6%) would contemplate having their cardioverter-defibrillator deactivated. 90.2% subjects considered it important for physicians to be interested in the views of patients regarding these issues. *Conclusion:* Despite the contrast with practice in some countries, most patients with cardiovascular disease would appreciate physicians being interested in their attitudes to the issue of end of life. An adequate level of information would help reduce patient concerns about their futures.

Keywords: advanced care, cardiovascular disease, communication, decision-making, end-of-life.

Introduction

Despite the impressive advances in cardiology over the past decades, heart disease continues to be the leading cause of death in countries of a high socioeconomic standard (Kojecký, Coufal, 2007; Sidney et al., 2016). Death is no longer a frequent complication of acute conditions in cardiology; people survive until chronic and end stages of heart disease, mainly chronic heart failure due to a host of causes; they are older, comorbid, and often undergo repeated hospitalizations (Christ et al., 2016). Some even require various types of mechanical support to stay alive (Lesny, 2016).

Although joint decision-making in compliance with patients´ best interests, and open communication with them and their families make up the principal components of care for incurable patients (Goodlin, 2009), the issue is generally neglected.

Aim

Our survey was designed to identify wishes and preferences related to the end of life of patients treated for cardiovascular (CV) diseases.

Methods

Design

Cross-sectional study.

Sample

Throughout 2016, 132 randomly selected patients receiving treatment for CV disease were offered the opportunity to complete an anonymous questionnaire containing 12 questions. The custom-made questionnaire reflected topics that are a common part of advanced care planning tools in the United States and Western Europe, e.g., Physician orders for life-sustaining treatment (POLST), or other types

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of Advance Directives. Some of the questions identified patient awareness as a basic condition for the competent planning of advanced care. Part of the questionnaire was also an evaluation of patients' interest in sharing their views on these issues with physicians. Eligibility criteria included absence of severely impaired cognitive function, current ability to read and write, and consent of patients. To ensure comprehensibility to even medically illiterate readers, every effort was made to formulate the questions as simply as possible, with no professional terminology.

The first set of people approached included hospitalized patients in a heart center ward of a regional hospital (with a catchment area of an approx. 0.5 million inhabitants), one day prior to discharge, so as to avoid traumatizing patients at a time when they are unsure about the outcome of their disease. Another set of patients consisted of cardiac outpatients on regular follow-up. The ward-based survey was conducted by an independent (out-of-house) physician, not by members of the attending staff.

Data collection

Prior to completing the questionnaire, the project goals were explained to each patient and they were assured that their answers would remain confidential; they were also assured that their answers would in no way affect their future treatment. Likewise, patients were informed that their participation in the survey, including completion of the questionnaire, was voluntary, and thus they were not obliged to receive the form, to answer any of the questions, or to submit the completed form. Voluntary completion of the questionnaire and its submission were considered equivalent to providing consent. No time limits were set for completing the questionnaire, and patients were able to ask about any items they did not understand, and/or make any comments about the survey.

The survey was approved by a local ethics committee of Tomas Bata Regional Hospital.

Data analysis

Analysis of data was performed using standard descriptive statistics. Categorical variables were expressed using absolute and relative frequencies. Continuous variables were expressed as means with standard deviation. Statistical significance of inter-group differences was determined using Pearson's chi-square test. The analysis was performed using the statistical software IBM SPSS Statistics for Windows, Version 24.0 (Armonk, NY: IBM Corp. Released, 2016).

Results

Of the 132 patients approached, 127 completed the questionnaire. Baseline characteristics of those surveyed are shown in Table 1.

Table 1 Patient characteristics

Patient characteristics		n (%)
Age, mean (± SD)		67.1 (± 12.8)
Gender	male	77 (60.6%)
	female	50 (39.4%)
Type of care	hospitalization	86 (67.7%)
	outpatient, follow-up	41 (32.3%)
Underlying diagnosis	heart failure	43 (33.9%)
	coronary heart disease	31 (24.4%)
	atrial fibrillation and supraventricular arrhythmia	9 (7.1%)
	ventricular arrhythmia	6 (4.7%)
	bradycardias	3 (2.4%)
	heart valve disease	3 (2.4%)
	hypertensive disease	21 (16.5%)
	other	11 (8.7%)
Disease duration	shorter than 1 month	23 (18.1%)
	1–12 months	7 (5.5%)
	1–10 years	46 (36.2%)
	over 10 years	48 (37,8%)
	not answered	3 (2.4%)
Experience of heart failure (at least one previous hospitalization for heart failure)		58 (45.7%)
Current hospitalization, primarily for heart failure		40 (36.4%)
First hospitalization for heart failure		11 (19.0%)
Re-hospitalization for heart failure		38 (64.4%)
Type of heart failure	systolic	46 (79.3%)
	with preserved ejection fraction	11 (19.0%)
	predominantly right-heart	1 (1.7%)
NYHA class	1	3 (5.2%)
	2	14 (24.1%)
	3	30 (51.7%)
	4	11 (19.0%)
Mean NYHA class (± SD)		2.8 (± 0.8)
ICD presence		17 (13.4%)
ICD implanted more than a year ago		9 (7.1%)
Experienced a discharge		4 (3.1%)

SD – standard deviation; NYHA – New York Heart Association; ICD – implantable cardioverter defibrillator

About two thirds of respondents were hospitalized patients, with the remaining third consisting of outpatients. Over half of the survey participants had experienced at least one major episode related to heart failure, most often due to left ventricular systolic dysfunction. The questions asked and percentages of answers are given in Table 2.

The patients statistically significantly most concerned about the future course of their disease were those aged 65–79 years (p = 0.044), inpatients (p < 0.001), those who felt they had insufficient information (p = 0.008), and patients either with newly diagnosed disease, or those with disease duration of over one year (p = 0.038) (Table 3).

Table 2 List of questions and percentage of answers

Questions	Answers	n (%)
1. Do you feel you have enough information about your disease?	yes	78 (61.9%)
	no	28 (22.2%)
	do not know	20 (15.9%)
2. Would you appreciate more information about your disease to be provided to people closest to you?	yes	54 (42.5%)
	no	49 (38.6%)
	do not know	24 (18.9%)
3. If able to choose, where would you like to spend your last days of life and die, would it be:	hospital	19 (15.4%)
	home	71 (57.7%)
	do not know	33 (26.8%)
4. Would you prefer spending the close of your life at home even the cost of less professional health care compared with that available in a hospital?	yes	70 (56.9%)
	no	30 (24.4%)
	do not know	23 (18.7%)
5. Do you think people can sense the impending stage of their lives, when further treatment to extend life is futile?	yes	60 (48.4%)
	no	25 (20.2%)
	do not know	39 (31.5%)
6. If forced to decide between receiving therapy extending life whatever the cost versus therapy that would make you feel better even at the cost of a shorter life, what would be your preference?	longer life even of lower quality	19 (15.4%)
	feel as fine as possible even at the cost of a shorter life	52 (42.3%)
	do not know	52 (42.3%)
7. Do you think that people have a right, at a time they still can reasonably make any decisions about themselves, to refuse resuscitation for himself/herself (= an effort to bring him/her back to life in cases where basic vital functions have failed)?	yes	50 (40.7%)
	no	37 (30.1%)
	do not know	36 (29.3%)
8. Would you yourself refuse resuscitation if sensing the end of life has arrived?	yes	48 (38.7%)
	no	38 (30.6%)
	do not know	38 (30.6%)
9. Some patients at higher risk of experiencing severe arrhythmias have had a cardioverter-defibrillator implanted (a device detecting arrhythmias and terminating them by a discharge). In theory, you may experience an episode of arrhythmia tomorrow... or after many months... or never. However, if it does come, the result may be sudden death. Can you imagine you would ever be interested in deactivation of the device? (e.g., in a situation whereby you feel very sick with your medications no longer effective?)	yes	29 (23.6%)
	no	41 (33.3%)
	do not know	53 (43.1%)
10. Who should make decisions about the above issues?	me	55 (45.1%)
	family	15 (12.3%)
	physicians	35 (28.7%)
	me and my family	3 (2.5%)
	me and physicians	6 (4.9%)
	my family and physicians	5 (4.1%)
	all of the above	3 (2.5%)
11. Do you think it useful for the physicians to be interested in your views about the above issues?	yes	111 (90.2%)
	no	4 (3.3%)
	do not know	8 (6.5%)
12. Are you concerned about future course of your disease?	yes	60 (47.6%)
	no	42 (33.3%)
	do not know	24 (19.0%)

An analysis comparing answers to other questions among various subgroups (men versus women; inpatients versus outpatients; disease duration; heart failure patients versus those with other diagnoses; individual NYHA classes; patients with versus without ICD, etc.) did not reveal any statistically significant differences.

The proportion of patients with an ICD was relatively small (n = 17; 13.4%). Of these only four (3.1%) had experienced at least one episode requiring a discharge. Among those wearing an ICD, three showed a theoretical interest in having the device deactivated. The characteristics they had in common can be summarized as follows: male gender; repeat hospitalizations for heart failure with reduced ejection fraction (NYHA II-IV); ICD implantation more than a year ago; confidence in having enough information about their condition; belief one can sense the end of life is near and that further therapy is futile; decision to refuse cardiopulmonary resuscitation in the above case.

Table 3 Concerns about future course of the disease

Categorized by						**p-value**[1]
Age			< 65 years	65–79 years	80 years and beyond	
Are you concerned about the future course of your disease?	yes		19 (44.2%)	36 (57.1%)	6 (28.6%)	0.044
	no		18 (41.9%)	13 (20.6%)	11 (52.4%)	
	do not know		6 (14.0%)	14 (22.2%)	4 (19.0%)	
Type of patient			inpatients	outpatients		
Are you concerned about the future course of your disease?	yes		50 (58.1%)	11 (26.8%)		< 0.001
	no		19 (22.1%)	23 (56.1%)		
	do not know		17 (19.8%)	7 (17.1%)		
Disease duration		< 1 month	< 1 year	1–10 years	> 10 years	
Are you concerned about the future course of your disease?	yes	14 (60.9%)	6 (85.7%)	19 (41.3%)	21 (43.8%)	0.038
	no	2 (8.7%)	1 (14.3%)	20 (43.5%)	17 (35.4%)	
	do not know	7 (30.4%)	0 (0.0%)	7 (15.2%)	10 (20.8%)	
Subjective perception of the level of information			Do you have enough information about your disease?			
			yes	no	do not know	
Are you concerned about the future course of your disease?	yes		32 (41.0%)	15 (53.6%)	13 (65.0%)	0.008
	no		35 (44.9%)	4 (14.3%)	3 (15.0%)	
	do not know		11 (14.1%)	9 (32.1%)	4 (20.0%)	

[1]*Statistical significance determined using Pearson's chí-square test*

Discussion

The issue of end-of-life preferences has not been explored to date within this cultural and historical context (i.e., central Europe, 27 years after the end of totalitarian rule); thus the survey provides a perspective that often differs on some issues commonly discussed or already resolved in countries with a long-standing tradition of societal and professional debate on the topic.

In the health systems of some countries, it is common for patients to be invited, at some point in their lives, to declare their views and ideas regarding the period when their disease has reached an advanced stage and they will be unable to formulate their views for themselves (living will, advance directives). While, in our survey, each patient also had the opportunity to write and have their will officially authorized regarding issues applicable to the advanced stages of their condition, this option was rarely taken.

In cardiology, it is not common to ask patients about their views and attitudes. The reasons may include lack of willingness, busy schedules, strict implementation of prevalent medical practice, lack of experience, or inability to communicate adequately. Regrettably, this situation persists at a time when available data attest to the advantages of training physicians in communication skills (Berlacher et al., 2017). In fact, the general rule in cardiology is to proceed strictly in line with current guidelines and historic practices. However, given the lack of data for patients in advanced stages of disease, it is common to extrapolate from results of studies conducted in populations with a substantially brighter future. This leads, not infrequently, to futile treatment at the very end of life (Willmott et al., 2016).

It is most likely that the high proportion of "Do not know" answers across all question sets in our survey is due to the absence of open communication on the issue of end-of-life preferences, or even long-standing "tabooization" of the topic. Prior to completing his form, one patient observed it was unethical for the physician to speak with patients about death in hospital, since "the physician is here to treat people and not to speak about death with them…". After a subsequent interview, he did complete the form, and even agreed that it was important for physicians to be interested in patients' views.

A negligible number of patients (n = 5; 3.8%) declined in advance to complete the questionnaire, or submitted it uncompleted. Studies by other authors have clearly shown that patients are interested in talking and being asked about the topic (Brunner-La Rocca et al., 2012; Gordon et al., 2017). This was confirmed by the overall positive response of our patients to the questionnaire (Table 2, question 11). Many found it necessary to comment more broadly on the questions.

Views of patients in the setting of our survey have not been given adequate attention to date, and, if we do learn their views, either proactively or accidentally, we are often unable or unwilling – whatever the reason – to take them into account (Cosgriff et al., 2007). A prevalent view is that the patient is not a professional and does not actually know what is in their best interests, is not versed in the current guidelines, and does not have the right to make decisions.

To carry out a meaningful dialog on these important topics, one of the main prerequisites is to provide the patient with as much information as possible regarding the nature of their disease, prognosis, and therapeutic options, all of which should be provided in a way that takes account of their intellect and current state of cognitive function (Harding et al., 2008). The authors of the present survey were pleased to find that almost two thirds of patients felt they had a sufficient level of information, reflected in a low degree of uncertainty. It is well known that uncertainty is a key component of the experience for patients with advanced disease. Better understanding and communication about uncertainty in the clinical setting can improve provision of information, help to engage and empower patients, and facilitate patient-centered care (Etkind et al., 2017).

42.5% of those surveyed would like a higher level of information to be provided to their family members. While physicians usually have little contact with the family of outpatients, among inpatients, the attitudes of the family vary significantly. One extreme is a situation in which several relatives come separately every day to ask the attending physicians about the patient's health status, therapy, and prognosis. The other extreme is social isolation, with those closest to the patient not only showing little interest in receiving information, but in some cases, not even visiting the patient at all. Hence, the wish for more information to be provided to relatives may mask a yearning for more interest on the part of those closest to them, a yearning for them to share their suffering and to appreciate their problems, and a need for support.

The place of death has been proposed as a measure of quality of end-of-life care (Teno et al., 2013). With patients dying in a hospital setting, components of end-of-life care that patients consider most important have been relatively well-defined (Virdun et al., 2017). Whilst only 15% of our respondents would prefer to die in a hospital setting, 56% would prefer to die at home (although this would mean less professional care than that available in hospital). This is in stark contrast with reality (Švancara et al., 2016).

About half of patients are convinced that a person can sense when the end of their life is very close and when any further intensive care will not substantially extend their lives. We do not know exactly the mechanism of perception of impending death, while experience shows that many patients do anticipate the impending end of life, objective data are unavailable. In principle, however, there is another major problem related to the following questions: "What if I have not reached the end stage of life yet but have refused resuscitation or any other invasive strategy that could possibly bring me back to life? What if I refuse any attempts to extend my life and give up too early?"

Only 15% of our patient set would prefer longer life even at the cost of lower quality of life. 40.9% of those surveyed suggested they would prefer a shorter life of higher quality without any major limiting symptoms. This is in contrast with real-world experience, whereby use of modern therapeutic strategies often helps to save lives, albeit at the cost of frequent readmissions to hospital, persisting severe symptoms, in-between hospitalizations, and prospects of further progressive worsening of patients' status. Authors of other studies report varied answers to similar questions, depending on the setting, type, stage of disease, study design, patient characteristics, and so on (Buchanan, Tan, 1997; Stanek et al., 2000; Lewis et al., 2001; Stevenson et al., 2008). Moreover, some attitudes and preferences change over time depending on the course of the disease and need for repeat hospitalizations. A sudden change may occur following the death of a partner (Fried et al., 2006). Our survey did not confirm anticipated differences related to age, inpatients versus outpatients, diagnosis, disease duration, and so on. Statistical analysis did not identify a set of variables capable of predicting which patients would prefer longer life to higher quality of life.

About 40% of those surveyed were confident that they had the right to refuse resucitation (Krumholz et al., 1998). Most respondents in this subgroup refused to be resuscitated. Real-life experience in the Czech Republic is in stark contrast to what our survey participants declared. In clinical practice, we rarely encounter patients who have explicitly requested a "Do not resuscitate" order.

22.8% of the surveyed population would theoretically consider ICD deactivation if they had the device implanted. Among the 17 ICD wearers in our survey, deactivation would be considered by three (17.6% of the subgroup with ICD implantation). According to current interpretation of the relevant Czech law, ICD deactivation is not allowed. On the other hand, the percentage of those considering device deactivation – at least theoretically – at some point of life is relatively low.

While almost half of those surveyed believed it was actually the patient who should make decisions about the above issues, the reality is quite different. It is not usual for patients to be proactively interested in the possibility of formulating their will in moments when they have reached the end stage and are unable to make any decisions about themselves and/or express their views. At the same time, patients are not encouraged by healthcare personnel to think about these topics, are not systematically educated, and, in most cases, do not have a say in making these most important decisions. 27.6% of respondents were happy with routine practice whereby physicians make the decisions. However, one cannot expect physicians to be aware of patients' preferences and/or thoughts at a time they are still able to formulate their views.

While 44.1% of patients would like to decide for themselves about critical aspects of their end of life, current practice is, as a rule, quite different. This may indicate the modesty, politeness, and low level of assertiveness of patients when expressing their views, perhaps even their loss of resolution in situations when their very lives are at stake. Unfortunately, this also indicates signs of persisting paternalism, and attests to a degree of inertia in physicians' attitudes and behavior.

An important outcome of the survey is the characteristics of the patients most worried about the future course of their disease: hospitalized patients aged 65–79, faced with heart disease for the first time, or, conversely, in a chronic stage of disease (for more over a year), and who feel they lack information about their diseases. It is these patients who should be given as much care as possible and should be provided with every available intervention by multidisciplinary teams to minimize their concerns and, hence, improve their quality of life.

Limitation of study

The main limitation of the survey is the relatively small number of patients. However, the conclusions are quite consistent with results of similar projects.

Another drawback is patient selection. Those in the worst condition and/or in the end stage of disease were not approached for ethical reasons, and concerns about potentially worsening their psychological condition. It is conceivable that if this patient subgroup had been included, the results would be markedly different. Likewise, approaching hospitalized patients shortly before discharge, i.e., at a time they are likely to be satisfied with the outcome and looking forward to a better future, will partly confound the generalizability and validity of answers. Our patients were not invited to fill in the questionnaire at the start of hospitalization – a time of uncertain prospects and concerns about their very survival, as this might have provoked a negative response. While the reasons for selecting patients with preserved cognitive function are self-explanatory, the survey omitted a population of polymorbid complexly disabled individuals whose answers, if reliably verifiable, might be most interesting.

Conclusion

In a society in which the topic has long been taboo, patients with cardiovascular disease are interested in sharing their views about the end of their lives, and preferences related to crucial aspects of their existence, with their physicians. Likewise, they appreciate receiving more detailed information about the nature of their disease and prospects. Informed patients await their future with less concern. Given the problems associated with creating a general model for characterizing patients and their respective end-of-life preferences, it is imperative to ask each patient repeatedly about their wishes, to take these into account, and incorporate them into joint decisions. This survey (at least in the setting in which it was conducted) is the first step on the road to filling the gap between patients' views and perspectives, and current everyday practice in cardiology.

Ethical aspects and conflict of interest

This study was approved by the Tomas Bata Regional Hospital ethics committee January 6, 2015 and has been performed in accordance with the ethical standards laid down in the 1964 Helsinki Declaration. All participants gave their informed consent prior to their inclusion in the study. No details that might disclose the identity of the participants under study is provided.

Acknowledgements

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Authors' contribution

Concept and study design (MG), data collection (MG, JS, VB), analysis and interpretation (JS), manuscript (MG), manuscript revision (ML), article finalisation (MG).

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