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ORIGINAL ARTICLE

Shared decision-making in advance care planning among hospitalized older COVID-19 patients: a multicenter, retrospective cohort study

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Abstract

Background In the Netherlands, it is customary to discuss directives regarding resuscitation, intubation, and ICU-admission with patients and/or their relatives upon hospital-admission. The outcome of this discussion is documented in a code status. Ideally, these advance care planning (ACP)-related decisions are made by a patient (and/or their relatives) and a professional together in a shared decision-making (SDM) process, to improve patient satisfaction and prevent undesired care. Given the bad outcomes in older COVID-19 patients, it is particularly important to discuss the code status upon admission. This study aims to describe the practice of SDM regarding code status during the COVID-pandemic. Specific aims were to find out to what extend patients took part in this decision-making process and whether all key elements of SDM for a shared decision were documented in medical reports.

Methods In this retrospective cohort study, we included COVID-19 patients aged 70 years and older, admitted to two large teaching hospitals in the Netherlands, during the first months of the COVID-19 pandemic in 2020. Data about code status and the decision-making process were extracted from electronic healthcare records.

Results Code status was documented for 274 of 275 included patients. Patient participation in the decision-making process was described in 48%. In 19% all key elements of shared decision-making have been described. Key elements of SDM were defined as the presence of a completed code status form, the presence of clinical notes showing that both patient's wishes and values and the opinion of the healthcare professional about the predicted outcome was taken into consideration and clinical notes of a patient–healthcare professional interaction during the admission.

Conclusion Our results show that a proper SDM process regarding code status is possible, even in hectic times like the COVID-19-pandemic. However, shared decision-making was not common practice in older patients with COVID-19 regarding code status (an ACP-related decision) in the early phase of the COVID-19 pandemic. Only in 19% of the patients, all key elements of SDM regarding code status were described.

Keywords COVID-19 · Code status · Older persons · Advance care planning · Shared decision-making

Introduction

Shared decision-making (SDM) is widely acknowledged as the best way of supporting patients in making decisions regarding their health and treatment [1]. During the process of SDM, clinicians aim to provide the patient with their professional opinion and expertise based on the best available evidence. Patients, in turn, share their personal preferences and goals. Based on these elements, the patient and clinician attempt to form a tailored treatment trajectory [2]. If successful, the result of this process is a thoroughly considered decision, acceptable for both the clinician and the patient [2, 3]. It creates comfort, improves patient satisfaction, and reduces undesired care in certain categories of patients [4]. Obviously, the relatives of the patient can also be involved in this process. Key elements in SDM are recognizing and acknowledging that a decision is required; awareness and understanding of the best available evidence regarding

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management options and potential harms, exploring the patient's values, preferences, and circumstances, and deciding together on the best option for the patient given his/her values, preferences, and circumstances [5, 6].

Advance care planning (ACP) is a process that enables patient and clinician to set up directives regarding future health care [7]. In the Netherlands, it is customary for a clinician to discuss directives regarding resuscitation, intubation, and ICU-admission with patients and/or their relatives upon hospital-admission. The outcome of this discussion is documented in a code status to prevent patients from being exposed to potentially harmful interventions with little to no chance on beneficial outcomes. Decisions such as these can be made based both on patients' personal wishes and on professional views and judgement. If possible, ACP-related decisions should be made by patient and/or their relatives and professional together and in consensus. This indicates that the process of ACP can be carried out using shared decision-making.

ACP is a process that, ideally, should take place before potential major acute lifesaving treatment like ICU-admission or resuscitation is needed. However, the process generally requires time and opportunity. Lack of time due to rapid deterioration of a patient can hinder the process of SDM and ACP. However, SDM is feasible in the emergency department (ED) and even in the fast-paced, chaotic environment of the ED with unfamiliar healthcare providers, most patients still wish to be involved in their care [6, 8].

During the COVID-19 pandemic, mortality rates in older patients admitted to the hospital with COVID-19 were high [9, 10]. Mortality was particularly high among older patients treated on ICU with mechanical ventilation [11, 12]. This information, combined with the fact that older patients generally experience significant functional decline after an ICU-admission [13], gives reason to assume that, in older patients with COVID-19, it was particularly important to discuss the code status upon admission.

It is unknown whether SDM was common practice in older patients with COVID-19 regarding code status. In this study, we analyzed the information regarding code status of older patients hospitalized with COVID-19 to see whether patients have participated in any way in the decision-making process. Furthermore, we wanted to know in how many patients all key elements/steps of the SDM process were described in patients' files to provide insight in how this process works in practice and to provide a view on how the implementation of SDM regarding code status can be improved.

Methods

Study design and setting

This multicenter, retrospective cohort study was conducted in the Catharina Hospital Eindhoven (CHE) and Amphia Hospital Breda (AHB), both large teaching hospitals in the Netherlands.

Study population

The study population consisted of patients aged 70 years or older, admitted for COVID-19 during the first wave of the COVID-19 pandemic in the Netherlands from February 25th till April 30th 2020. SarsCoV-2 infection was confirmed by (real-time) polymerase chain reaction testing material obtained by nasopharyngeal swabs. Patients were excluded if they were transferred to other hospitals.

Data sources

Patient data on demographics, comorbidities, code status, outcomes, and the decision-making process were extracted from electronic healthcare records (EHR). Comorbidities were scored using the Charlson Comorbidity Index (CCI) [14]. Treatment limitations were categorized into 'cardiopulmonary resuscitation' (yes/no), 'ICU admission' (yes/no), 'invasive mechanical ventilation' (yes/no), and 'others'. Code status may change in the course of hospital stay, especially in the first days, because of possibly required peer consultation or extended conversation with the patient. Therefore, we used the code status documented 3 days after admission. A fac-simile of a code status is displayed in Fig. S1 of supplementary information.

All daily clinical notes in the EHR system were actively studied (VJJH, JBLvdM, ESJ) to further obtain detailed information about which treatment limitations were in place and how this decision was made by whom and when. If the information was unavailable or inconclusive, 'unknown' was noted as a result.

The SDM process was evaluated based on the information available in the EHR system. We studied whether a decision-making process had taken place and if so, if the elements of the SDM process as described by Légaré et al. [5] and Probst et al. [6] were considered.

Patient participation in a decision-making process was defined as the situation in which the patients' wishes were known and described or a conversation with the patient, regarding his or her code status was documented.

The presence of all key elements was defined as follows. A complete SDM process starts with the recognition that a decision is required. Therefore, the presence of a completed

Table 1 Baseline characteristics in 275 Dutch patients aged 70+ years admitted to hospital with COVID-19

Characteristics	Total ($n=275$)
Age, median (range)	78.0 (70–94)
Sex	
Female	100 (36%)
Male	175 (64%)
Median CCI (range)	2.0 (0–8)
Median hospital length of stay in days (range)	7.0 (1–67)
In-hospital mortality	125 (45%)

CCI, Charlson Comorbidity Index

code status form was considered as being the first step. Other key SDM elements (knowing and understanding the best available evidence regarding management options and potential harms, exploring the patient's values, preferences and circumstances, and deciding together [5, 6]) were considered present when clinical notes were found showing the fact that both patient's wishes and values and the opinion/knowledge of the healthcare professional about the predicted outcome were taken into consideration and discussed in a patient-healthcare professional interaction during the admission.

Analytical/statistical methods

Data were analyzed using SPSS software version 25.0 (IBM, Armonk, NY, USA). Total counts and percentages are given for categorical values and median with interquartile range for continuous variables. Chi-square analysis was performed on categorical variables and the Mann–Whitney test on continuous variables.

Results

A total of 275 hospitalized patients (64% men, 175 CHE, 100 AHB) with verified SARS-CoV-2 infection were included. Median age was 78 years. Baseline characteristics are presented in Table 1.

Code status was documented for 274 (99.6%) patients. Full active treatment was documented in 74 patients (27.0%), and in 200 patients (72.7%), one or more treatment limitations were documented. In 84% of patients with one or more treatment limitations, the following code status was documented; no resuscitation, no mechanical ventilation, and no ICU-admission. Distribution of the code statuses is displayed in Fig. S2 of supplementary information.

Patients with one or more treatment limitations were older, had a higher Charlson Comorbidity Index, and had a higher in-hospital mortality rate than patients without treatment limitations. Results are depicted in Table 2.

Table 2 Characteristics and outcome in patients with and without treatment limitations

	Patients without treatment limitations ($n=74$)	Patients with one or more treatment limitations ($n=200$)	*P* value
Age, mean (95% CI)	74.6 (73.8–75.5)	80.7 (79.9–81.6)	0.000
Sex (%/number female)	31%/23	39% /77	0.269
CCI, mean (95% CI)	1.49 (1.08–1.87)	2.64 (2.37–2.89)	< 0.001
Hospital length of stay in days, mean (95% CI)	11.0 (8.2–13.9)	8.5 (7.7–9.5)	0.787
In-hospital mortality (%/number)	23%/17	54%/108	< 0.001

CCI, Charlson Comorbidity Index; *CI*, confidence interval

Table 3 Documented information about the SDM process in the ACP/code status consideration

	Patients without treatment limitations (n = 74)	Patients with one or more treatment limitations (n = 200)	Total (n = 274)
Patient was informed about code status in current hospital-admission (%/number)	93%/69	96%/191	95%/260
Patient participated in decision-making process[a] (%/number)	27%/20	56%/112	48%/132
All key elements of shared decision-making have been described[a] (%/number)	8%/6	23%/46	19%/52

[a]definitions described in methods

In 95% of the patients, it was documented that the patient was informed about code status in current hospital-admission. Patient participation in the (S)DM process was described in 48% of the cases; in 19% of the patients, the SDM process was fully completed and documented (Table 3). Patients without treatment limitations participated significantly less in decision-making (27%) in contrary to patients with one or more treatment limitations (56%). Furthermore, in patients without treatment limitations, key elements for decision-making were more frequently missing (Table 3).

In 45% (24 in absolute numbers) of the patients in which all key elements of SDM were described, there was a difference in opinion between the patient and the medical team regarding advance care treatment, chances on recovering, and life expectancy. In patients in which not all key elements were described, it is not known whether there was a difference, since either the patients' wishes were unknown or either the opinion of the medical team.

Discussion

This retrospective multicenter cohort study describes the practice of SDM in a population of SARS-CoV-2-infected older patients in the early phase of the COVID-19 pandemic. The results show that more than half of the patients (52%) did not participate in the decision-making process about their code status. Only 19% of the patients were involved in a fully finalized SDM process including careful documentation. Reasons for this low compliance might be the fact that we were not able to verify if SDM might have taken place without documenting it properly afterwards. This hypothesis might find support in the findings that in almost half (45%) of the patients in which all key elements of SDM were described, there was a difference in opinion between the patient and the medical team regarding advance care treatment, chances on recovering, and life expectancy. This might lead to a more extensive discussion and to a more extensive documentation. Agreement between patient and professional, on the contrary, might lead to a more concise and brief documentation about the patients' wishes, which was the most important item in our definition of patient participation in the decision-making process. Our hypothesis is that agreement on code status occurs more often in patients without treatment limitations than in patients with treatment limitations. We believe that this is the reason why patients without treatment limitations participated significantly less in decision-making (27%) compared to patients with one or more treatment limitations (56%).

Reports about SDM, ACP, and code status in the COVID-19 context are scarce. The process of SDM has been studied earlier in a general ER environment and showed a 49% compliance rate using a composite instrument [15]. Other research has shown that there was no difference in frequency of code status documentation in COVID-19 patients opposed to the pre-COVID cohort [16].

In almost all patients (99.7%), code status was documented in the EHR and most patients (95%) have been informed about their advance directives about resuscitation, intubation, and ICU-admission during their hospital-admission. Briedé et al. found in a similar population that code status was documented in 69.8% [16]. In the AHB, it is mandatory for a clinician to complete a code status form before the patient leaves the emergency department, and we hypothesize that our high percentage of code status documentation has to do with this mandatory code status form. This could mean that incorporating such a module in the EHR could help healthcare professionals to think and talk about the code status, which is one of the key elements of shared decision-making: acknowledging that a decision is required. We also believe that incorporating the key elements of SDM in the mandatory code status form could improve attainment of a shared decision.

The most important limitation of the present study is that, as stated before, this study effectively focused on what was documented in the EHR, which might not be the representation of the actual conversation that took place. Furthermore, some data were susceptible to inter-observer variations. Definitions for these outcomes were set up and used to minimize the effect of inter-observer variations.

We believe that the results of this study help to understand how the process of shared decision-making regarding code status (an ACP-related decision) worked in daily clinical practice during the beginning of the COVID-19 pandemic. Increasing knowledge and communication skills could help to implement shared decision-making [17]. For example, by training doctors on how to discuss advance directions with the patients and make sure that they have the knowledge to inform patients properly about the expectations. Informing patients using visual material with explanation about CPR and intubation might help in making an informed decision [18]. Also, the introduction of a form that needs to be completed in the EHR before ending the consult might overcome undercompliance. Finally, if available, involvement of the general practitioner or other doctors caring for the patients, in discussing the code status at an earlier stage, add to the knowledge of both patients and healthcare professionals about personal values and wishes.

Further research is needed to find out if these measures will lead to a higher compliance in following the correct process of SDM including proper documentation.

Conclusion

A standardized SDM procedure regarding code status is feasible, even in hectic times like the COVID-19-pandemic. However, shared decision-making was not common practice in older patients with COVID-19 regarding code status (an ACP-related decision) in the early phase of the COVID-19 pandemic. Almost all patients have been informed about their code status, but only half of them participated in the decision-making process and in only 19% of the patients all key elements of SDM regarding code status have been described.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s40520-022-02281-y.

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Declarations

Conflict of interest All authors declare that they have no conflict of interest.

Ethical approval The medical research ethics committees united (MEC-U) waived the necessity for formal approval of the study, as data collection followed routine practice (registration number W21.051).

Statement of human and animal rights This article does not contain any studies with animals performed by any of the authors.

Informed consent Informed consent was not obtained, since data collection followed routine practice.

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