

Original Article

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Patient–physician conversations about life-sustaining treatment: Treatment preferences and participant assessments

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Abstract

Objective. In 2019, the Danish parliament issued legislation requiring Danish physicians to clarify and honor seriously ill patients' treatment preferences. The American POLST (Physician Orders for Life-Sustaining Treatment) document could be a valuable model for this process. The aim of the study was to examine patients' preferences for life-sustaining treatment and participant assessment of a Danish POLST form.

Methods. The study is a prospective intervention based on a pilot-tested Danish POLST form. Participant assessments were examined using questionnaire surveys. Patients with serious illness and/or frailty from seven hospital wards, two general practitioners, and four nursing homes were included. The patients and their physicians completed the POLST form based on a process of shared decision-making.

Results. A total of 95 patients (aged 41–95) participated. Hereof, 88% declined cardiopulmonary resuscitation, 83% preferred limited medical interventions or comfort care, and 74% did not require artificial nutrition. The preferences were similar within age groups, genders, and locations, but with a tendency toward younger patients being more in favor of full treatment and nursing home residents being more in favor of cardiopulmonary resuscitation. Questionnaire response rates were 69% (66/95) for patients, 79% (22/28) for physicians, and 31% (9/29) for nurses. Hereof, the majority of patients, physicians, and nurses found that the POLST form was usable for conversations and decision-making about life-sustaining treatment to either a high or very high degree.

Significance of results. The majority of seriously ill patients did not want a resuscitation attempt and opted for selected treatments. The majority of participants found that the Danish POLST was usable for conversations and decisions about life-sustaining treatment to either a high or a very high degree, and that the POLST form facilitated an opportunity to openly discuss life-sustaining treatment.

Introduction

Advanced care planning (ACP) requires thoughtful, facilitated conversations between health-care professionals and patients. If patients partake in treatment discussion, physicians acquire a greater understanding of patients' treatment preferences (Murray et al., 2013; Brinkman-Stoppelenburg et al., 2014). Patients with serious illness generally prefer to be involved in decisions regarding their serious medical problems (Gorton et al., 2008; Schoenfeld et al., 2018), and preferred location of end-of-life care (Waller et al., 2018). Yet, recent studies have found an urgent need to improve the quality of communication between healthcare professionals and patients living with serious illness (Lakin et al., 2016; Chen et al., 2017; Tulskey et al., 2017; Bergenholtz et al., 2019; Habib et al., 2019; Paladino et al., 2019, 2020; Douglas et al., 2020). Inadequate communication with patients about their treatment preferences may lead to nonbeneficial treatment and end-of-life (EOL) care (Mack et al., 2010; Douglas et al., 2019).

Shared decision-making is on the political agenda in Denmark (Dahl Steffensen et al., 2017), and in 2019, the Danish parliament issued legislation requiring Danish physicians to clarify seriously ill patients' treatment preferences. Worldwide, the COVID-19 pandemic has illuminated the importance of goal-concordant EOL care, so that scarce resources are not used on patients who do not opt for them (Curtis et al., 2020; McIntosh, 2020). Therefore, discussing and documenting preferences for resuscitation and life-sustaining treatment in advance of a medical crisis are becoming increasingly important.

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A number of countries have ACP guidelines and forms, some of which are limited to specific patient groups, eliciting treatment instructions about goals and preferences for future medical care (Rietjens et al., 2017; Jimenez et al., 2018). However, ACP is a concept yet to be implemented in many countries (Meeussen et al., 2011; Gjerberg et al., 2015; Petri et al., 2020). One of the most used and researched ACP tools is the American Physician Orders for Life-Sustaining Treatment (POLST) (Hickman et al., 2015; Moss et al., 2017). The POLST form is designed for seriously ill or medically frail patients. The POLST form should be completed following a serious illness conversation and shared decision-making. During the conversation, the patient shares his or her values, belief, and goals for care, and the healthcare professional elucidates the patient's diagnosis, prognosis and treatment alternatives, including the benefits and burdens of life-sustaining treatment. Together, they then reach an informed decision about desired treatment (Hickman et al., 2015).

The aim of the current pilot study was to examine patients' preferences for life-sustaining treatment and participant assessment of a Danish POLST form.

Methods

Participants

To include a diverse range of participants, study sites in hospital wards, general practitioners' offices, and nursing homes from four out of five Danish regions were invited to participate. The first author visited all sites, introduced the project to relevant staff members, and supplied written instructions and project material. After the introduction, staff members at each site identified and included eligible patients. The study was conducted from September 2018 to July 2020.

Inclusion criteria

The patient inclusion criteria were as follows: (i) 18 years or older; (ii) patients with serious illness and/or frailty for whom the physician considered death within the next 12 months to be likely; (iii) the ability to read and understand Danish; and (iv) no known cognitive impairment.

POLST form

From August 2017 to July 2018, a Danish version of a POLST form based on the US POLST form (National POLST, 2020) was developed and pilot-tested with participants from hospital wards, general practitioners' clinics, and nursing homes. The process was evaluated by questionnaires and in-depth interviews. The Danish POLST form includes three areas: cardiopulmonary resuscitation, level of treatment (comfort measures only, selected treatment, and full treatment), and artificially administered nutrition (Supplementary Material A).

POLST conversation

Aided by the POLST form, the physician and patient engaged in a conversation about patient values, beliefs, goals for care, diagnosis, prognosis, and treatment alternatives. Depending on the patients' wishes, one or more family members and/or nursing staff could participate. After the conversation, the patient's treatment preferences were registered, and documented in the patient's

medical records, as the POLST form is not yet a Danish legal document. The healthcare professionals did not receive specific education in conducting POLST conversations, but the project material included a list of "helpful prompts and questions" to initiate, conduct, and conclude the conversation.

Evaluation

The completed POLST forms provided baseline demographics including setting-related characteristics, age, gender, and treatment preferences of the patients. Seven days after completing the POLST document, patients and participating family members were forwarded a questionnaire. Physicians and nurses received the questionnaire after completing their last POLST conversation to prevent multiple responses. The questionnaire was used for identifying perspectives about the POLST form itself, to identify if the patient previously had discussed preferences for life-sustaining treatment, and to identify if the participants found the POLST form useful in facilitating the conversation and making decisions about life-sustaining treatment.

Questionnaire survey

The questionnaires were developed based on the literature, US POLST research and experiences from the pre-pilot testing of the Danish POLST form (POLST toolkit; Stacey et al., 2017). The questionnaires consisted of eight to nine questions and were similar for all participant groups with the exception of questions about background characteristics and the time required to complete a POLST form (Supplementary Material B). All patients and family members could complete the questionnaire either on paper or by e-mail through the online system REDCap (Research Electronic Data Capture). All physicians and nurses received the questionnaire by e-mail/REDCap. If questionnaires had not been returned within three weeks, a reminder was sent by e-mail or phone.

Data analysis

In this study, only patients, physicians, and nurses' perspectives were included, as all data from family members will be analyzed in a future study. Study data were collected, managed, and analyzed using REDCap electronic data capture tools hosted at OPEN, Open Patient data Explorative Network, Odense University Hospital, Region of Southern Denmark. Quantitative data were analyzed using descriptive statistics. Qualitative data (comments) nuanced the results.

Ethics

All participants were informed verbally and in writing that participation was voluntary, all data were collected confidentially, and it was possible to withdraw from the study at any point without explanation. All participants gave written consent to participate in the POLST conversation and the subsequent questionnaire survey. The Committee on Health Research Ethics for Southern Denmark assessed that the study did not require ethical approval according to Danish law (March 29, 2017). The study was approved by the Danish Data Protection Agency (1732459). To ensure data security, a License agreement was obtained with OPEN (Open Patient data Explorative Network) (OP_504).

Results

A total of 95 out of the 120 patients invited to a POLST decision-making conversation accepted (79%). Additionally, 28 physicians participated in the conversations, and 29 nurses participated in the conversations and/or the administrative part of the study. Patients were included from 13 sites: seven hospital wards [oncology, hematology (two wards from different hospitals), nephrology/dialysis, pulmonary medicine, neurology, and geriatrics], four nursing homes, and two general practitioners. The physicians reported that the conversations in general had lasted less than 15 min (27%), between 15 and 24 min (50%), or between 25 and 35 min (23%). The patients included were between 41 and 95 years of age, and the majority of participants were from hospital wards (Table 1).

Treatment preferences

The majority of patients did not want a resuscitation attempt, opted for limited treatments, and did not want artificial nutrition (Table 2).

Table 3 presents treatment preferences combined with patient characteristics. The preferences were similar within age groups, genders, and locations, but with a tendency toward younger patients being more in favor of full treatment and nursing home residents being more in favor of CPR (Table 3).

Questionnaire survey

The response rate was 69% (66/95) for patients, 79% (22/28) for physicians, and 31% (9/29) for nurses. The group of patients who filled in the questionnaire was similar to the whole group of patients (Table 1). The participating physicians had a mean age of 46 years, 50% were female, and they were from hospital wards (64%), nursing homes (9%), and general practitioners (27%). The participating nurses had a mean age of 48, 100% were female, and they were from hospital wards (67%), nursing homes (22%), and general practitioners (11%).

A total of 84% of the patients found that the level of information in the POLST form was appropriate. Likewise, 78% of the participating nurses and 91% of the physicians wanted to neither add nor remove any information. A total of 67% of patients had discussed preferences for life-sustaining treatment prior to being invited to this study. Hereof, 54% had discussed their preferences with family, 18% with general practitioners, 32% with hospital physicians, 8% with friends, and 18% with other.

As shown in Table 4, the majority of all participants perceived that the POLST document was usable for conversations and decisions about life-sustaining treatment to either a high or very high degree.

Comments

A number of participants added comments to elucidate their responses: both those highly in favor of the POLST form, and those who found it useful to some or a lesser degree. Table 5 presents citations that represent the comments.

The comments illuminate why the majority of patients and healthcare professionals found the POLST form relevant for engaging in a conversation and making decisions about life-sustaining treatment. They described the conversation as relevant, necessary, bringing forth an openness and providing an

Table 1. Baseline age, gender, and setting-related characteristics of patients who completed a POLST form and responded to the questionnaire

	Patients who completed a POLST form <i>n</i> = 95	Patients who completed a POLST form and responded to the questionnaire <i>n</i> = 66
Age (years), Range (mean, SD)	41–95 (77, 11)	41–95 (78,10)
Gender, <i>n</i> (%)		
Female	55 (58)	34 (52)
Male	40 (42)	32 (48)
Type of setting, <i>n</i> (%)		
Hospital	62 (65)	42 (63)
Nursing home	17 (18)	13 (20)
General practitioner	16 (17)	11 (17)

Table 2. Treatment preferences among 95 patients who completed a POLST form

Danish POLST	<i>N</i>	%
A Cardiopulmonary Resuscitation (CPR):		
Attempt Resuscitation (CPR)	11	(12)
Do <i>Not</i> Attempt Resuscitation (DNR)	84	(88)
B Medical Interventions:		
Comfort Measures Only	21	(22)
Limited Treatment	58	(61)
Full Treatment	16	(17)
C Artificially Administered Nutrition		
Do administer artificial nutrition by tube and/or IV	25	(26)
Do <i>NOT</i> administer artificial nutrition by tube and/or IV	70	(74)

opportunity to make preferences known. However, one patient experienced that the usability depended on the participants in the conversation, and several healthcare professionals found the POLST form too rigid.

Discussion

Most patients did not want a resuscitation attempt and opted for limited treatments. The majority of all participants found that the Danish POLST was usable for conversations and decisions about life-sustaining treatment to either a high or a very high degree, and that the POLST form facilitated an opportunity to openly discuss life-sustaining treatment. A majority of the patients had previously discussed their preferences for level of treatment.

Patient preferences in the current study are similar to other studies. Yip *et al.* found that 79% of patients declined CPR and 83% preferred limited medical interventions or comfort care (Yip *et al.*, 2020), and a recent US POLST study showed that 87% declined CPR and 89% preferred limited medical interventions or comfort care (Zive *et al.*, 2019). The fact that the majority of seriously ill patients do not want CPR or full treatment underlines the need for conducting an ACP conversation while the

Table 3. Treatment preferences combined with age, gender, and setting-related characteristics

Study	Section A: Resuscitation		Section B: Medical Interventions			Section C: Artificial Nutrition	
	Attempt Resuscitation (CPR)	Do Not Resuscitate (DNR)	Comfort Measures	Limited Treatment	Full Treatment	Artificial Nutrition	No Artificial Nutrition
Age, n (%)							
40–64	1 (7)	14 (93)	4 (27)	6 (40)	5 (33)	5 (33)	10 (66)
65–74	2 (11)	17 (89)	3 (16)	12 (63)	4 (21)	8 (42)	11 (58)
75–84	3 (9)	32 (91)	5 (14)	26 (74)	4 (12)	6 (17)	29 (83)
85+	5 (19)	21 (81)	9 (35)	14 (54)	3 (11)	6 (23)	20 (77)
Sex, n (%)							
Female	6 (11)	49 (89)	13 (24)	35 (63)	7 (13)	13 (24)	42 (76)
Male	5 (13)	35 (87)	8 (20)	23 (58)	9 (22)	12 (30)	28 (70)
Location, n (%)							
Hospital	4 (6)	58 (94)	12 (19)	39 (63)	11 (18)	18 (29)	44 (71)
Nursing Home	5 (29)	12 (71)	5 (29)	9 (53)	3 (18)	3 (18)	14 (82)
General Practitioner (GP)	2 (12)	14 (88)	4 (25)	10 (63)	2 (12)	4(25)	12 (75)

Table 4. Participants’ assessment of the POLST form

	Patients	Physicians	Nurses
To which degree did you find that the POLST form was usable to <i>talk about</i> wishes for levels of life-sustaining treatment?			
	n (%)		
To a very high degree	15 (24)	6 (27)	3 (33)
To a high degree	29 (47)	10 (46)	3 (33)
To some degree	16 (26)	4 (18)	3 (33)
To a lesser degree	1 (2)	2 (9)	0
Not at all	0	0	0
Not applicable ^a	1 (2)	0	0
To which degree did you find that the POLST form was usable to <i>make decisions</i> for levels of life-sustaining treatment?			
To a very high degree	12 (20)	5 (23)	3 (33)
To a high degree	24 (41)	9 (41)	3 (33)
To some degree	18 (31)	7 (32)	3 (33)
To a lesser degree	1 (2)	1 (4)	0
Not at all	0	0	0
Not applicable ^a	4 (7)	0	0

^aNot applicable as decisions were made ahead of the POLST conversation.

patient still has decision-making capacity, as physicians’ goals may not be in accordance with those of patients (Douglas et al., 2020). An ACP conversation can help ensure that the patients do not receive unwanted and nonbeneficial treatment and end-of-life care (Douglas et al., 2019; Mack and Dosa, 2020). If no ACP conversation has been conducted and the patient does not have decision-making capacity, family members are important sources for information on the patient’s values and preferences.

Table 5. Comments from questionnaire survey participants regarding the usability of the POLST form for conversations and decisions about life-sustaining treatment

Participants who considered the POLST document usable to either a high or very high degree	Participants who considered the POLST document usable to either some or a lesser degree
It was good to be given the opportunity to talk about it, rather than have family decide for me, if I become incapable — Patient ID25	It depends a lot on who participates in the conversation — Patient ID30
It is completely relevant — Patient ID55	Decisions were already made ahead of the conversation, so I didn’t need it as I had talked with my general practitioner about it — Patient ID45
It legitimizes and facilitates the necessary conversation — Physician ID2	I support the idea of a more formalized and consistent conversation about levels of treatment, but I dislike the contract-looking design — Physician ID67
The openness that emerges from the conversation is good, as the relatives or the patient might have assumptions about how to protect the other party, or not want to cause distress — Nurse ID51	I find it too rigid to use the form. I prefer to talk with the patient more freely about it — Nurse ID61
It was good to talk about such serious questions early in the course of my illness — Patient ID86	The section about treatments — full treatment or selective treatment — is confusing — Patient ID89

However, family members’ beliefs about patient preferences may be inaccurate (Shalowitz et al., 2006) and often represent their own wishes for the patient (Marks and Arkes, 2008). Understanding the patient’s preferences for life-sustaining treatment reduces the burden for family members (Detering et al., 2010).

The majority of participants found that the Danish POLST was usable for conversations and decision-making for life-sustaining treatment to either a high or very high degree. This aligns with studies showing that ACP promotes conversations and positively impacts the quality of end-of-life care (Detering *et al.*, 2010; Brinkman-Stoppelenburg *et al.*, 2014) and patient and family satisfaction (Detering *et al.*, 2010). The free text comments elucidated why most of the participants found the ACP conversation useful.

Most seriously ill patients want a conversation about level of treatment (Gorton *et al.*, 2008; Schoenfeld *et al.*, 2018), but there are a number of reasons why this is not happening: lack of invitations from healthcare professionals may prevent patients from engaging in decision-making (Heyland *et al.*, 2013; Joseph-Williams *et al.*, 2017; Schoenfeld *et al.*, 2018); Also, training of clinicians in serious illness communication identified a number of barriers to communication: lack of knowledge about how to approach end-of-life communication, variation in attitudes about the appropriate time to initiate this, time constraints and concerns regarding patient reluctance (Paladino *et al.*, 2019). Finally, novel treatments may cause prognostic uncertainty and add to the difficulty of finding the right words to balance hope with concern (LeBlanc *et al.*, 2018; Chu *et al.*, 2020). In a study by Wright *et al.*, no differences were found in levels of fear and anxiety in terminally ill cancer patients who had EOL discussions compared with those who did not (Wright *et al.*, 2008), so fear of patient distress in connection with end-of-life conversations may be over-estimated. Hence, there is a need to improve the quality of communication between healthcare professionals and patients living with serious illness (Tulsky *et al.*, 2017; Bergenholtz *et al.*, 2019).

Although a few of the participants in the current study found the form rigid, most of the participants still found having a form helpful for both initiating and conducting a conversation about preferences for life-sustaining treatment. However, it is important that the patient is given the opportunity to share his or her values, beliefs, and goals for care, and that the healthcare professional explains the patient's diagnosis, prognosis, and treatment alternatives (Curtis *et al.*, 2020). From ICU studies, it is known that if families are allowed to speak more during ICU End-Of-Life conferences, they are more satisfied (McDonagh *et al.*, 2004). When families of dying ICU patients were randomized to a proactive conference (talking 47% of the time) versus a normal conference (talking 25% of the time), there was less family posttraumatic stress disorder (PTSD) in the proactive group (Lautrette *et al.*, 2007). Both of these studies elucidate the value of physicians listening instead of talking and this is equally essential when discussing levels of treatment.

The tendency toward nursing home residents more in favor of CPR than other respondents was somewhat surprising. The small number of nursing home participants entails that this result should be interpreted with caution. But if verified in further studies, it may be due to lack of information on or understanding of the low success rate of a resuscitation attempt if cardiac arrest is due to chronic disease or frailty (Libungan *et al.*, 2015). Understanding prognosis and consequences is not easy (Chen *et al.*, 2017), and as low health literacy is more prevalent among older adults (Zamora and Clingerman, 2011), it emphasizes the need for having easy-to-understand information and materials available making appropriate health decisions (Nouri *et al.*, 2019). The Danish POLST form does not yet include an exclusion function (e.g., it is not possible to opt for no CPR and full treatment at the same time) and several patients expressed these contradicting preferences. Contradicting preferences elucidates the need for

thorough information of the possible consequences of different choices, as well as a need for further research (Schmidt *et al.*, 2014).

Of the patients who completed the questionnaire, 67% had discussed level of treatment prior to the POLST conversation. Similar to the current study, Waller *et al.* (2019) found that more patients had discussed end-of-life issues with family members than with physicians. The fact that so many in the current study have discussed treatment options underlines the importance of these discussions.

The participating sites were asked to consecutively invite eligible patients. However, many sites included fewer patients than initially expected and several additional sites never included patients despite their initial enthusiasm. This could indicate that when the possibility of a conversation arose, some physicians (despite their good intentions) refrained from conducting the conversation after all. Therefore, even though 79% of the invited patients agreed to participate, this probably did not represent 79% of eligible patients.

Strengths of the study include the variety of clinical settings, data from different regions of Denmark, urban versus rural parts of the country, and the high physician response rate. In addition, a thorough pilot study was conducted, ensuring that the format of the POLST form and questionnaire worked in Denmark and was pilot tested in all the sites included in the study (data not yet published). Limitations include it being a single national study and the low number of participants, which entails that the results mainly are hypothesis generating, especially the subgroup analyses. Likewise, the response rates (only fair for patients and low for nurses) entail the risk of nonresponder bias, possible selection bias in the inclusion of patients. Several nurses wrote that they only processed the POLST forms and had not participated in the actual conversations, but had mistakenly registered as participants. The physicians did not receive the questionnaire until the end of the inclusion period. As some sites only included a few patients and at various times throughout the inclusion period, there may have been long periods between conversations and the survey in some cases. Additionally, the survey for physicians and nurses coincided with the COVID-19 pandemic, which probably influenced response rates and definitely impacted negatively on the number of patients that were able to be included. The conversations were not observed, and therefore the quality of the conversations has not been monitored. Even though the physicians were thoroughly introduced to the study, there is no proof that they actually talked with the patients about their prognosis, goals and values before decisions were made. This should be examined in further research. Likewise, the reasons behind patient preferences were not examined.

Conclusion

The majority of seriously ill patients did not want a resuscitation attempt and opted for selected treatments. The wishes for life-sustaining treatment were similar within age groups, genders, and locations. The majority of participants found that the Danish POLST was usable for conversations and decisions about life-sustaining treatment to either a high or very high degree, and that the POLST form facilitated an opportunity to openly discuss life-sustaining treatment.

Supplementary material. The supplementary material for this article can be found at <https://doi.org/10.1017/S1478951521001875>.

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Author contributions. HIJ and HHB designed the study with input from LDT, ASÅ, EF, and ST. LDT had main responsibility for data collection and analyses and drafted the manuscript. All authors provided inputs throughout the study process, all critically reviewed the content of the paper and approved the final version.

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Conflict of interest. There are no conflicts of interest.

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