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Reasons for Discordance and Concordance between POLST Orders and Current Treatment Preferences

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Abstract

Background—The reasons for discordance between advance care planning documentation and current preferences are not well understood. The POLST form offers a unique opportunity to learn about the reasons for discordance and concordance that has relevance for POLST as well as advance care planning generally.

Design—Qualitative descriptive including constant comparative analysis within and across cases.

Setting—26 nursing facilities in Indiana.

Participants—Residents (n=36) and surrogate decision-makers of residents without decisional capacity (n=37).

Measurements—A semi-structured interview guide was used to explore the reasons for discordance or concordance between current preferences and existing POLST forms.

Findings—Reasons for discordance include: 1) problematic nursing facility practices related to POLST completion; 2) missing key information about POLST treatment decisions; 3) deferring to others; and 4) changes over time. Some participants were unable to explain the discordance due to a lack of insight or inability to remember details of the original POLST conversation. Explanations for concordance include: 1) no change in the resident's medical condition and/or the resident is unlikely to improve; 2) use of the substituted judgment standard for surrogate decision-making; and 3) fixed opinion about what is "right" with little to no insight.

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Author Contributions

Author Contributions were as follows: Study concept and design (SEH, GAS, AMT, RS, BJH); acquisition of subjects and/or data (SEH, ALM, NHS); analysis and interpretation of data (SEH, GAS, AMT, ALM, NHS, RS, BJH), and preparation of manuscript (SEH, GAS, AMT, ALM, NHS, RS, BJH).

Conflict of Interest

The authors report no conflicts of interest.

Conclusion—Participant explanations for discordance between existing POLST orders and current preferences highlight the importance of adequate structures and processes to support high quality advance care planning in nursing facilities. Residents with stable or poor health may be more appropriate candidates for engaging in advance care planning conversations than residents with a less clear prognosis, though preferences should be revisited periodically as well as when there is a change in condition to help ensure existing documentation is concordant with current treatment preferences.

Keywords

Nursing home; advance care planning; palliative care

INTRODUCTION

Advance care planning (ACP) documentation is not always concordant with preferences, as reflected by studies suggesting preference discordance in 70% of cases or more for older, seriously ill hospitalized patients[1] and nursing facility residents.[2] However, the reasons for discordance are unclear. Prior research has largely focused on questions related to the stability of treatment preferences over time.[3,4] Although preference instability is an important factor in understanding discordance, there may be other explanations that provide direction for intervention.

POLST is a medical order widely used in nursing facilities[5] to document the treatment preferences of seriously ill patients.[6] POLST offers a unique opportunity to identify and better understand the reasons for discordance between current preferences and orders by providing clear documentation of previous decisions. In order to better understand the reasons for discordance between current preferences and documentation, a qualitative study was undertaken as part of a larger, NIH-funded study of POLST decision-quality in the nursing facility setting.[7]

METHODS

Setting

This study was conducted at 26 Indiana nursing facilities[8] between August 2016 and February 2019. The protocol was reviewed and approved by the Indiana University Institutional Review Board.

Participants

Participants were nursing facility residents with decisional capacity and surrogate decision-makers for residents without decisional capacity. Eligibility criteria included: 1) a completed POLST form signed by the person being interviewed; 2) resident length of stay ≥ 60 days; 3) resident aged 65 or older; and 4) fluency in English. Participants were screened using the Telephone Interview for Cognitive Status (TICS)[9] and a consent verification process[10] was used to ensure capacity to consent to participation. Because patients and surrogates may have different experiences with decision-making,[11] we included approximately equal

numbers of each. We also selected participants with concordant orders and preferences as negative cases to more fully understand reasons for discordance.[12]

Procedures

Medical records were reviewed to identify potentially eligible participants and to abstract POLST orders. Current treatment preferences were elicited using a standardized interview tool. Participants were interviewed about the reasons for discordance or concordance between current preferences and existing POLST orders. Interviews were recorded and professionally transcribed.

Data Collection Tools

Participant Characteristics.—Age, race, gender, and education level, and surrogate relationship to resident were obtained during the interview. Health literacy was assessed using a previously validated self-report tool.[13,14]

Current Treatment Preferences.—The Respecting Choices Advanced Steps interview was used to elicit current, values-based, informed POLST preferences for cardiopulmonary resuscitation, medical interventions, and artificial nutrition.[15]

Existing POLST Orders.—Orders for cardiopulmonary resuscitation, medical interventions, and artificial nutrition were abstracted from the residents' POLST form.

Discordance/Concordance Interview.—Participants were asked to reflect on the reasons for discordance or concordance between current preferences and existing POLST orders. (See Supplementary Text S1 for interview guide).

Qualitative Analysis

Well-established qualitative descriptive techniques guided analysis of the data.[6,16] Analysis was conducted using open coding of interview data line by line to inductively identify and label ideas. We then used constant comparative analysis across cases to identify themes and subthemes until theme saturation was achieved.[17] NVivo was used to manage the data.[18] The first 16 discordance transcripts were independently read and coded by at least three members of the team to identify themes related to the reasons for discordance. A preliminary list of codes was developed and refined as additional interviews were coded. Subsequent interviews were coded by a minimum of 4 coders who met periodically to refine the common list of codes and to discuss emerging themes. Coding continued until theme saturation was achieved and differences in interpretations of data were discussed. A coding dictionary and memos tracked coding decisions. A similar process was used to code the concordance interviews. Because themes were similar between residents who made their own decisions and surrogate decision-makers, we combined the analyses for these two groups.

RESULTS

Participant Characteristics

There were 26 residents and 25 surrogates in the discordance sample and 10 residents and 12 surrogates in the concordance sample. (See Tables 1 and 2).

Discordance Themes

Initial analysis resulted in 29 discordance codes that were collapsed into four themes. (See Table 3).

Problematic Nursing Facility Practices.—Participants described two different practices that contributed to discordance: asking participants to complete the POLST independently without any discussion or support and staff not accurately recording preferences. Several participants described filling the POLST form out as part of the admission process without any discussion or support from nursing facility staff. This approach was problematic both because participants felt overwhelmed by the admissions process and because they lacked adequate information to make decisions.

In other situations, it appeared there were errors in how the form was filled out, either due to clerical errors made by the person filling out the form or misunderstandings about preferences. Discordance stemming from misunderstandings was not as clearly attributable to a particular process, such as including the POLST form in admissions paperwork.

Missing Information.—Another reason for discordance was a lack of information about how POLST works, available treatment options, and the resident's medical condition. These knowledge gaps were addressed in the course of the Advanced Steps interview.

Deferring to Others.—In some situations, surrogates indicated that preference discordance was a result of deferring to other family members or nursing facility staff during the decision-making process. Other surrogates reported having less strongly held opinions than other family members or a desire to avoid conflict. Residents reported slightly different reasons for deferring to others, suggesting the discordance was attributable to their decision to rely on family for decision-making.

Re-evaluating What is Best.—Preference discordance was also due to changes in the participant's thinking about what is "best" compared to when the original form was completed. Reasons for rethinking included new experiences and observations, reassessment of potential benefits and burdens in relation to the goals of care, as well as changes in health (both decline and improvement). Although most often these changes resulted in a preference for less intervention, it sometimes led to a preference for more intervention.

The Inability to Explain or Remember.—Some participants reported that they could not remember the prior conversation or signing the form, and therefore did not know why the form did not match current preferences. Others expressed more broadly that they really did not know why things were different and seemed to lack insight. This explanation was seen almost exclusively in interviews with residents.

Concordance

Saturation was reached more quickly in the concordance sample. The initial analysis resulted in 14 concordance codes that were collapsed into 3 themes (see Table 3).

No change in medical condition/unlikely to improve.—Several participants indicated there was no reason to re-evaluate prior decisions because the resident's condition was stable or on a clear, downward trajectory and the form already reflected a focus on comfort.

Substituted judgment.—Some surrogates indicated that they made their decisions based on what they understood the resident would want and that they had no new information to support making a different choice.

Stable preference/no insight.—This concordance theme was reflected by comments reiterating the prior decision without further elaboration.

DISCUSSION

Study findings suggest that inadequate processes to support ACP include an apparent failure to provide important information necessary to support informed decision-making and suboptimal timing of ACP can lead to preference discordance. Some participants reported low quality or non-existent conversations that lacked relevant information about the resident's medical condition and treatment options or did not include an adequate assessment of how well participants understood the information provided. These practices are inconsistent with guidelines for appropriate use of POLST[5] and advance care planning best practices[19]..

A related process issue that emerged is a failure to revisit decisions when there were changes in the residents' medical condition. This is particularly problematic given that some episodes of discordance were attributed to an improvement or decline in residents' health, changes which should trigger a review of ACP decisions and POLST orders. There is evidence suggesting that some instances of discordance are identified and resolved at the time treatment decisions are made.[20–22] Other participants reported new insights that changed the decision-maker's perspective on whether to accept or decline life-sustaining medical interventions. These examples point to the need to revisit ACP decisions on a regular basis as part of the standard of care, not as a one-time activity.[5,19] These problematic practices are not addressed by current regulations, which only require nursing facilities offer advance directives and maintain policies but provide no standards for best practice policies, procedures, or training.[23]

The fact that some participants reported deferring to others is not surprising given that most people are concerned about how health care decisions impact family and friends.[24] Several surrogates reported deferring to family members, suggesting consideration of factors beyond residents' prior stated preferences or the best interest standard[25] including a desire to avoid family conflict.[26] Residents' decisions to defer to others seemed to reflect delegated autonomy and a decision to relinquish decision-making responsibilities, a preference

reported by many older adults.[27,28] Although one surrogate reported being swayed by the recommendation of clinical staff (possibly reflecting shared decision-making), there were no reports of coercion to make specific decisions counter to one's own preferences.

It is less clear how to address discordance in situations where the participants either did not remember the conversation or had no insight. This could be due to several factors, including completing the form under suboptimal conditions (e.g., on admission), when people may be stressed or feel unwell. However, it may also be that the discussion was forgotten because it was not memorable, it occurred too long ago, or the participant's memory was failing.[29] It is debatable whether forgetting the original discussion and/or decision invalidates the process used to make the decision. The inability to explain discordance may also reflect the impact of more subtle cognitive impairments on medical decision-making.[30] Although most older adults with mild dementia can participate in medical-decision-making, these individuals may struggle with the more complex medical decision-making raised by POLST due to difficulties understanding information[30–32] or engaging in rational reasoning.[31] These findings suggest the need for more decision-support for residents and surrogates when completing POLST to compensate for subtle cognitive deficits that are not necessarily obvious to staff.[31]

In contrast, residents and surrogates with concordant documentation reported that decisions were unchanged due to a clear clinical picture or clear preferences. These findings are consistent with Fried et al,[4] who interviewed older adults prospectively and found that about half had stable preferences over time. Additionally, several surrogates noted that their decisions were unchanged because they were using substituted judgment and basing decisions on their understanding of the resident's preferences, highlighting the value of identifying and including surrogate decision-makers in advance care planning conversations.[33]

It is also possible that discordance and instability are due not to unstable preferences, but weakly held preferences. There is evidence that some people are less invested in engaging in this kind of decision-making.[34,35] This notion raises important questions about whether these individuals should even be asked to complete POLST or whether it is more appropriate to work with a trusted surrogate or provide more directive treatment recommendations.

Limitations.

The study was completed in a single, relatively homogenous state and with a largely white sample. Residents and surrogate decision-makers were interviewed individually, although some participants noted that other family members and health care providers had been involved in the original decision. Interviewing these individuals jointly may have revealed additional reasons for discordance. Additionally, the length of time between the original decision and the interview may have introduced recall bias hampering the recollection of both the conversation and relevant information used as the basis for decisions.

Conclusions

Findings highlight the need for nursing home policies and practices that support high quality ACP discussions. ACP documentation tools like POLST should never be handed out at the

time of admission with the expectation that residents and or surrogates should complete the form without the support of members of the health care team. Instead, ACP should be voluntarily completed based on a conversation with a health care provider who has ACP facilitation skills.[5,19] Policies and practices that support high quality ACP discussions should include on-going training for staff, facility wide education, and routine as well as clinically-triggered re-assessments of preferences. Training should include education about POLST treatment options, how to assess comprehension, and strategies to meaningfully revisit treatment preferences at regular intervals. These improvements have the potential to increase concordance between ACP documentation and current treatment preferences.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Key Points

1. The reasons for discordance and concordance between current preferences and POLST orders are complex and varied.
2. Changes are needed to nursing home policies and practices to support high quality ACP discussions.
3. Residents with stable or poor health may be more appropriate candidates for engaging in advance care planning conversations than residents with a less clear prognosis.

Why does this paper matter?

Identifying reasons for discordance between current preferences and existing POLST orders provides directions for practice improvements.

Table 1.

Characteristics of participating decision-makers: discordant interviews (n=51).

Characteristic	Residents (n=26)	Surrogates (n=25)
Age, mean (±SD)	79.9 (± 8.6)	63 (±8.8)
Gender, female	21 (80.8%)	19 (76%)
Race		
White	23 (88.5%)	21 (84%)
Black or African American	1 (3.8%)	2 (8%)
American Indian or Alaska Native	1 (3.8%)	0
More Than One Race	1 (3.8%)	2 (8%)
Ethnicity		
Hispanic/Latino	1 (3.8%)	0
Relationship to resident		
Spouse	n/a	3 (12%)
Child/child-in-law		15(60%)
Niece/nephew		4 (16%)
Grandchild		2 (8%)
Friend		1 (4%)
Schooling		
Some high school	4 (15.4%)	0
Graduated high school	8 (30.8%)	7 (28%)
College and above	14 (53.8%)	18 (72%)
Telephone Interview for Cognitive Status Score, mean (±SD)[a]	30.6 (± 3.1)	36.2 (±2.7)
Health Literacy, mean (±SD)[b]	1.5 (± 0.7)	0.9 (± 0.8)

[a]TICS™ (Telephone Interview for Cognitive Status) score is a measure of cognition, where scores <20 indicate moderate to severe impairment, 21–25 indicates mild impairment, 26–32 indicates ambiguous cognitive status, and 33–41 indicates no impairment.[13]

[b]Health literacy score ranges from 0–4, where higher scores indicate lower health literacy.[13,14]

Table 2.

Characteristics of participating decision-makers: concordant interviews (n =22).

Characteristic	Residents (n=10)	Surrogates (n=12)
Age, mean (±SD)	85.6 (±8.3)	61.17 (±9.6)
Gender, female	7 (70%)	7 (58.3%)
Race		
White	9 (90%)	10 (83.3%)
Black or African American	1 (10%)	1 (8.3%)
American Indian or Alaska Native	0	1 (8.3%)
Ethnicity		
Hispanic/Latino	0	0
Relationship to resident		
Spouse	n/a	2 (16.7%)
Child/child-in-law/stepchild		8 (66.7%)
Sibling		1 (8.3%)
Grandchild		1 (8.3%)
Schooling		
Some high school	0	0
Graduated high school	4 (40%)	2 (16.7%)
College and above	6 (60%)	10 (83.3%)
Telephone Interview for Cognitive Status Score, mean (±SD)[a]	28 (±3.8)	35.67 (±2.8)
Health Literacy, mean (±SD)[b]	1.7 (±0.9)	1.0 (±0.9)

[a]TICS™ (Telephone Interview for Cognitive Status) score is a measure of cognition, where scores <20 indicate moderate to severe impairment, 21–25 indicates mild impairment, 26–32 indicates ambiguous cognitive status, and 33–41 indicates no impairment.[13]

[b]Health literacy score ranges from 0–4, where higher scores indicate lower health literacy.[13,14]

Table 3.

Resident and Surrogate Reasons for POLST Preference Discordance and Concordance.

Reasons for Discordance	
Problematic Nursing Facility Practices	*"When I was doing them (the POLST decisions), I was doing a stack of papers. I was signing my name and signing my name and signing my name. So after a while you get a little blurred." (resident)*
	"I was having to answer tons of questions. It wasn't just the POLST form. That was just another sheet of paper that I had to fill out. There was all kinds of paperwork that you have to do when you're putting somebody in a long term facility. So I barely even remember even filling it out. I can't necessarily say I wasn't comfortable with it or I was because I don't really remember. There was so much stuff that I wasn't comfortable with at that time." (surrogate)
	"...And see, like I said before when I was filling it out, there wasn't anybody to explain anything...." (resident)
	"Well I kind of had a little bit of trouble getting (staff member) to understand some of the decisions I made..." (resident)
Missing Information	*"And that goes back to the pneumonia that you mentioned. That's something I had never considered, something that she could recover from. I mean even at this point in her life I think she could possibly come back from that. I just had never considered it... when I did this paperwork I was thinking more and even all the way up to today I was thinking more of lung cancer, COPD, heart failure or something like that." (surrogate)*
	"Like I said, I knew with CPR about the ribs as a potential danger, but I don't know that I knew all the details about the breathing tube." (surrogate)
Deferring to Others	*"I might have answered the question that way [on POLST] for my younger sister's benefit because she is so, oh my gosh, it's hard for her to accept anything. Mom and dad is going to live forever. We all know that's not true." (surrogate)*
	"I think I had stronger input from family members and I kind of just acquiesced because it made sense at the time." (surrogate)
	"*My daughter does everything for me.*" (resident)
Re-evaluating what is best	*"I feel like now he has declined so much from [when the POLST was completed]. He's been on hospice. I just feel like making the rest of his life just comfort, not thinking about prolonging it, just thinking more about his comfort and making the best of the time that we have left, rather than putting him through things that probably aren't going to make a difference anyway." (surrogate)*
	"...actually I think she's doing better since she is there. They make her get up and they can get her to the bathroom and they can get her to do the things that she needs to do... I think her health is a little bit better. So that's probably a little bit of [the reason for the change in preference]." (surrogate)
Inability to remember or explain	*"I don't know why. Especially since that was after I had gone to the hospital because I really don't know why (resident)."*
	"That's a hard decision to make. I can't explain why... It just seems to me that that would be a better choice at this point (resident)."
Reasons for Concordance	
No Change/Unlikely to Improve	*"Because nothing has changed, and nothing is going to change. [The resident] is not going to get better." (surrogate)*
	"Well it might be that I feel pretty close to the same." (resident)
	"Because of what I've been told by the doctors and what I'm seeing when I see her how she's going downhill and I just want her, if anything happens, I just want her to be comfortable. I don't want any tubes and things connected to her." (surrogate)
Substituted Judgment	*"I know that's what dad wanted and he and my mom had both, they had everything all planned out so it wasn't hard to go ahead and do that because I knew what he wanted." (surrogate)*
Stable Preferences/No Insight	*"I made the choices three years ago and I guess I really meant them." (resident)*
	"It's just what I think." (resident)