UNIVERSIDADE ESTADUAL PAULISTA
"JÚLIO DE MESQUITA FILHO"
FACULDADE DE MEDICINA

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# Avaliação da confiabilidade interobservadores e validação de construto do formulário POLST (Physician Orders for Life-Sustaining Treatment) para documentação de preferências de cuidados no fim da vida

Tese apresentada à Faculdade de Medicina, Universidade Estadual Paulista "Júlio de Mesquita Filho", Câmpus de Botucatu, para obtenção do título de Doutor em Saúde Coletiva.

Orientador: Prof. Dr. Edison Iglesias de Oliveira Vidal.
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**Botucatu**
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*Dedicatória*

*Dedico esse trabalho a todos os pacientes e seus familiares que se dispuseram a contribuir, de forma pioneira, com o fomento científico em nosso país por meio do compatilhamento de seus valores e preferências ao final de suas vidas. Confiaram em nosso grupo de pesquisa para expor os mais íntimos sentimentos e desejos.*

*Mesmo não sendo o intuito dessa pesquisa neste momento, espero que tenhamos contribuido de alguma forma para que esses pacientes e seus familiars tenham obtido maior autonomia e dignidade nesse momento de suas existências.*

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*"Somos como borboletas que se agitam por um dia e pensam que é para sempre."*

*Carl Sagan*

# Resumo

**RESUMO**

No Brasil a maior parte dos profissionais e instituições de saúde ainda se encontram longe de constituírem uma rotina de discussão sobre preferências de cuidados no fim da vida junto a pacientes com prognóstico reservado. Esta corresponde a uma grande lacuna na atenção à saúde em nosso país, a qual frequentemente se associa a sofrimento evitável de pacientes e familiares, bem como ao mau uso dos recursos disponíveis no Sistema Único de Saúde (SUS). Em 1991 nos Estados Unidos da América, foi iniciado um programa de discussão de preferências de cuidados no fim da vida denominado POLST *(Physician Orders for Life-Sustaining Treatment*). Trata-se de um sistema coordenado para evocar, documentar e comunicar as preferências de pacientes/familiares quanto a tratamentos prolongadores da vida para enfermos com expectativa de vida reduzida, de forma a orientar as condutas médicas em diferentes cenários de cuidados. Em nossa revisão de literatura identificamos a inexistência de estudos de avaliação da validade de construto ou da confiabilidade interobservadores desse formulário. Portanto, com o intuito de produzir dados que subsidiem a implantação do paradigma POLST no Brasil, a presente pesquisa teve como objetivo avaliar essas propriedades psicométricas desse instrumento, já adaptado para o Brasil, de acordo com o referencial do COSMIN (*Consensus-based Standards for the selection of health Measurement Instruments).* Dessa forma obtivemos como resultado dois artigos.

O primeiro artigo avaliou a confiabilidade interobservadores do instrumento, ou seja, a estabilidade das prescrições de tratamentos médicos no fim da vida documentadas em formulários POLST quando pesquisadores diferentes entrevistavam em dias distintos um mesmo participante da pesquisa seguindo uma abordagem padronizada. De um total de 64 participantes entrevistados, houve 5 (8%) casos de discordância na comparação entre avaliações envolvendo ao menos uma das prescrições médicas de cuidados no fim da vida. A estatística Kappa revelou níveis elevados de concordância interobservadores em todos os itens do instrumento.

O segundo artigo analisou a validade de construto do formulário POLST, ou seja, se as prescrições médicas documentadas por meio do instrumento refletiam as preferências de cuidados dos pacientes estudados conforme registaradas seguindo uma outra abordagem. A hipótese testada foi que a prescrição de cuidados no final da vida contida nos formulários POLST apresentaria elevado nível de concordância com a documentação em texto livre de entrevistas realizada por um médico experiente em cuidados paliativos seguindo a proposta de Sudore & Fried para discussões de planejamento antecipado de cuidados. Dos 62 pacientes entrevistados, houve 7 (11%) casos de discordância relativas a ao menos uma das prescrições de tratamentos no fim da vida, sendo que a análise dos dados utilizando da estatística Kappa novamente evidenciou elevada concordância entre as duas abordagens.

Em conclusão, por um lado os resultados dos estudos que compõem essa tese fornecem evidências acerca da confiabilidade interobservadores e da validade de construto do formulário POLST, o que certamente contribuirá para a futura implantação desse paradigma no Brasil. Por outro lado, o fato de terem sido observados casos de discordâncias em ambas as pesquisas ressalta a complexidade envolvida em qualquer processo de planejamento antecipado de cuidados e aponta para a necessidade de que prescrições de tratamentos médicos

no fim da vida registradas em formulários POLST sejam revisadas com frequência de modo a confirmar que as mesmas são consistentes com as preferências atuais dos pacientes.

**Palavras-chave:** POLST. Reprodutibilidade dos testes. Estudos de validação. Planejamento antecipado de cuidados. Diretivas antecipadas.

## ABSTRACT

In Brazil, most healthcare professionals and institutions still have not included discussions about preferences of care at the end of life with patients with decreased life expectancy as part of their daily routine. This represents a major gap in the care at the close of life in our country, which is often associated with the avoidable suffering of patients and their loved ones, as well as the misuse of Public Health resources. In 1991 the Physician Orders for Life-Sustaining Treatment (POLST) was started in the United States. It is a coordinated system to elicit, document and communicate patients' and families' preferences regarding life-sustaining treatments for individuals with reduced life expectancy across a variety of different healthcare settings.

In our literature review we identified that there were no studies evaluating the construct validity or the inter-rater reliability of the POLST form. Therefore, with the intent of producing data to support the implementation of POLST in Brazil, we aimed to evaluate the inter-rater reliability and the construct validity of the POLST form that we had previously adapted to Brazil. We followed the COSMIN (Consensus-based Standards for the selection of health Measurement Instruments) guidelines when designing our methods and reporting our findings. As a result, we produced two articles.

The first article evaluated the interrater reliability of the POLST form, i.e., the stability of medical orders for treatments at the end of life recorded in those forms when two different researchers interviewed the same participant on different days following a standardized approach. Out of 64 participants that we interviewed, there were 5 (8%) cases of disagreement between the interviews regarding at least one medical order documented in the POLST forms, which yielded Kappa statistics with high levels of agreement for all items of the instrument.

The second article evaluated the construct validity of the POLST form, i.e., whether the medical orders recorded in POLST forms reflected preferences of care documented following another approach. We tested the hypothesis that medical orders in POLST forms would show high levels of agreement with the free-form text documentation of an advance care planning conversation performed following the proposal of Sudore & Fried by and experienced palliative care physician. Out of 62 patients that we interviewed, there were 7 (11%) cases of disagreement between at least one medical order recorded in POLST forms and the free-form text documentation of the other advance care planning conversation, which again yielded Kappa statistics with high levels of agreement for all items of the POLST form.

In conclusion, on the one hand our results provide evidence on the interrater reliability and construct validity of the POLST form, which will be instrumental for the future implementation of the POLST paradigm in Brazil. On the other hand, the

finding of cases of discordances regarding medical orders in POLST forms highlights the complexity involved in any advance care planning process and points towards the need to revise medical orders in POLST forms frequently to confirm that they accurately reflect patients' current preferences for care.

**Keywords:** POLST. Reproducibility of tests. Validation studies. Advance Care Planning. Advance Directives.

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# *Introdução*

## INTRODUÇÃO

O século passado foi palco de mudanças importantes na forma como as sociedades ocidentais vivenciam o fim da vida. Para muitas pessoas a principal fonte de preocupação relacionada ao fim da vida deixou de ser a ocorrência de uma morte precoce e passou a ser a da possibilidade de uma morte tardia, ocorrendo lentamente através do prolongamento indevido da vida pelos avanços da tecnologia médica em situações de dependência e sofrimento contrárias a seus valores individuais.[1,2]

As Unidades de Terapia Intensiva (UTI) se popularizaram entre as décadas de 50 e 60 do século XX para oferecer aos pacientes monitorização contínua e intervenções médicas que potencialmente poderiam reverter distúrbios fisiológicos e salvar vidas. Com o advento dessas unidades diversas situações clínicas previamente incompatíveis com a vida deixaram de sê-lo e a própria distinção entre “salvar uma vida” e “prolongar uma morte” tornou-se menos clara.[3,4] Grande parte da equipe médica e das instituições de saúde assumiam que as intervenções mantenedoras da vida propostas nas UTIs eram naturalmente benéficas e justificadas. Refletindo essa premissa e utilizando-se do modelo paternalista de tomada de decisão predominante na época, a equipe médica frequentemente iniciava a maior parte dos tratamentos, incluindo intervenções invasivas e prolongadoras da vida sem a obtenção de consentimento informado de pacientes ou de seus familiars.[5] Tal tipo de conduta se fundamentava na concepção bioética predominante àquela época, a qual se pautava eminentemente nos princípios de beneficência e não-maleficência.[6] Após a introdução das técnicas de compressão torácica e desfibrilação elétrica na década de 1960 a não realização destas técnicas em todos os casos de parada cardiorrespiratória era considerada como antiética e ilegal, como se representasse uma forma de “eutanásia passiva”. Entretanto, com o passar do tempo, ficou claro que a efetividade das novas tecnologias para a recuperação do nível neurológico prévio frequentemente

se limitava a uma pequena minoria dos pacientes e surgiram questionamentos éticos acerca das intervenções médicas voltadas ao suporte de vida.[7]

De forma contemporânea à disseminação das UTIs e à expansão das possibilidades de manutenção artificial da vida, estabelecia-se paulatinamente o princípio da autonomia dentro da bioética occidental.[5,8] A introdução deste princípio como um componente fundamental da bioética se deu frente a uma conjunção de fatores envolvendo desde a constatação das atrocidades cometidas durante o regime nazista em nome da pesquisa médica até os movimentos pelos direitos civis das mulheres e de minorias étnicas. Adicionalmente diversos processos judiciais nos EUA contribuíram para o estabelecimento da necessidade de consentimento de pacientes acerca dos tratamentos propostos pelos profissionais de saúde bem como seu direito de declinar tais procedimentos mesmo frente a situações que de outro modo conduziriam à sua morte.[3,5,8] Finalmente as décadas de 50 e 60 veem surgir no Reino Unido o movimento *Hospice* traduzindo uma nova inquietação social com os cuidados de saúde oferecidos no fim da vida e buscando assegurar uma morte digna aos portadores de doenças ameaçadoras da vida.[9]

Dentro desse contexto histórico e como resposta às preocupações relacionadas ao tipo de cuidados que as pessoas receberiam no fim de suas vidas surgem as diretivas antecipadas de vontade (DAV) de vontade relacionadas à saúde. A primeira DAV foi proposta na forma de um testamento vital (“*living will*”) em 1969 por um advogado norte-americano de nome Luis Kutner como uma estratégia para permitir que as preferências de cuidado das pessoas fossem respeitadas mesmo em situações de estados futuros de saúde em que as mesmas se encontrassem incapazes de decidir sobre tratamentos de saúde que consentiriam ou não em receber.[4,8] Ao longo do tempo surgiram diferentes tipos de documentos com finalidade semelhante e o termo DAV passou a referir-se a qualquer documento escrito que descrevesse os desejos do paciente em relação a

seus cuidados de saúde frente a uma situação futura eventual de incapacidade de tomada de decisão. De forma geral as DAV foram classificadas em diretivas de processo e diretivas substantivas.[10] As diretivas de processo correspondem essencialmente a documentos onde os pacientes apontam seus representantes para tomada de decisões relacionadas à saúde. Já as diretivas substantivas, ou testamentos vitais, documentam os valores e as preferências de cuidados de saúde dos pacientes podendo incluir ou não a designação de um representante para tomada de decisão.

Apesar de inúmeros esforços políticos e legais para a disseminação do uso das DAV entre os pacientes nos EUA (e.g. *Self-determination act* de 1990) diversos problemas impediram que as DAV atingissem plenamente seu objetivo de honrar os desejos das pessoas em relação a seus cuidados de saúde no fim da vida.[3,4,10,11] Por exemplo, frequentemente DAV existentes eram inacessíveis quando necessárias (e.g., quando algum familiar acionava indevidamente serviços de emergência pré-hospitalar). Além disso, muitas vezes, mesmo quando uma DAV era acessível ela se mostrava de pouca relevância devido a abordagens vagas ou específicas demais em sua redação que a invalidavam quando diante da necessidade de tomada de decisão frente a uma série de situações que não haviam sido antecipadas previamente. Finalmente, mesmo quando disponíveis e relevantes para as situações clínicas em questão, muitas vezes sua validade legal era questionada devido a uma abordagem excessivamente legalista que terminava por minar a própria utilidade das DAV.

Como resultado desse quadro as últimas décadas vem sendo palco de uma mudança de paradigma no campo da tomada de decisão sobre cuidados de saúde no fim da vida, onde a ênfase deixou de recair sobre a elaboração de um documento e passou a se dar sobre o processo de discussão acerca dos valores, preferências e expectativas de pacientes e familiares; bem como sobre a instrução de representantes para a tomada de decisão de forma compartilhada com a equipe médica em tempo real

com base nas perspectivas pessoais descortinadas previamente.[4,10,12]

Tal processo de discussão foi denominado de Planejamento Antecipado de Cuidados (PAC). Embora o foco principal desse tipo de planejamento se constitua no processo de diálogo longitudinal estabelecido entre pacientes, profissionais de saúde e familiares / representantes, o produto de tais discussões permanece sendo documentado na forma de uma DAV. Essa mudança de foco permitiu que o PAC demonstrasse através de diversos estudos uma maior frequência de respeito às preferências de cuidados dos indivíduos no fim da vida, uma redução no sofrimento de familiares, uma melhor qualidade de vida de pacientes próximos ao fim da vida e uma melhor recuperação de seus entes queridos durante o luto.[13, 14]

Em 1991 no estado de Oregon nos EUA, foi iniciado um programa de discussão de preferências de cuidados no fim da vida denominado de POLST *(Physician Orders for Life-Sustaining Treatment*). Este programa representava um sistema coordenado para evocar, documentar e comunicar as preferências de pacientes/familiares quanto a tratamentos prolongadores da vida para enfermos com expectativa de vida reduzida, de forma a orientar as condutas médicas em diferentes cenários de cuidados (domicílio, ambulância, pronto socorro, ambulatório e hospital).[15,16] Para tanto foi utilizado um formulário de cores vibrantes onde eram documentadas prescrições médicas baseadas nas preferências de cuidados dos pacientes quanto a ressuscitação cardiopulmonar e uma variedade de intervenções médicas desde intubação traqueal até antibioticoterapia e nutrição/hidratação artificial. Pela objetividade e portabilidade do instrumento, este se difundiu pelos EUA e atualmente representa uma das principais e melhor sucedidas estratégias para a elicitação e documentação de preferências de cuidados no fim da vida naquele país. Há evidências crescentes de estudos observacionais demonstrando tanto a eficácia da estratégia de documentação de preferências de cuidado no fim da vida através do POLST como sua

superioridade quando comparada a estratégias tradicionais no que tange à probabilidade de honrar tais preferências.[17-21]

Quando comparado a outros instrumentos existentes com a mesma finalidade, como o “*Five wishes*”, o “Preferences for Care Near the End of Life”, e a “End-of-life preferences interview” o POLST apresenta diversas vantagens e tem sido considerado como um marco importante na história do planejamento de cuidados no fim da vida.[3,4,13,15,22–24] Dentre as principais vantagens cabe listar sua simplicidade e objetividade de registro das informações, o fato de constituir-se como “prescrições médicas” baseadas nas preferências de cuidados de saúde dos pacientes tendo em vista seu estado de saúde atual – e não um estado futuro hipotético –, sua portabilidade entre diferentes cenários de cuidados de saúde e fato de atualmente cobrir um contingente populacional crescente e superior a qualquer outro instrumento existente.

# *Justificativa*

## JUSTIFICATIVA

Um importante relatório avaliando a qualidade da morte no mundo, comparou o ambiente de cuidado no final da vida, a disponibilidade de cuidados especializados para o fim da vida, os custos envolvidos e a qualidade do cuidado prestado em 40 países.[25] O Brasil foi avaliado como um dos piores locais para se morrer, à frente apenas de Índia e Uganda. Após cinco anos o mesmo estudo foi repetido, dessa vez abarcando 80 países. Embora não ocupasse mais a antepenúltima posição no índice de qualidade de morte, o Brasil caiu 4 posições e passou para o 42º lugar da lista de países avaliados.[26]

Em agosto de 2012 o Conselho Federal de Medicina aprovou a resolução 1995 que define e regulamenta as diretivas antecipadas de vontade no âmbito do exercício da medicina no Brasil. Mesmo após a ratificação da constitucionalidade desta resolução pelo Juizado Federal em fevereiro de 2014, a maior parte dos profissionais e das instituições de saúde ainda encontram-se longe de constituírem uma rotina de discussão sobre preferências de cuidados no fim da vida em nosso país. Esta corresponde a uma grande lacuna na atenção à saúde e que frequentemente se associa a sofrimento evitável de pacientes e familiares bem como ao mal-uso dos recursos disponíveis no Sistema Único de Saúde (SUS). Por outro lado, mesmo quando tais discussões ocorrem, seu registro frequentemente é inacessível no momento de complicações agudas em que decisões sobre intervenções prolongadoras da vida devem ser tomadas em tempo real.

Recentemente foi concluída a adaptação transcultural do formulário POLST para o Brasil.[27] Em nossa revisão de literatura e em consulta ao Comitê Nacional do POLST nos EUA identificamos que até o momento não há estudos de avaliação da confiabilidade interobservadores ou da validade de construto desse formulário. Isto se deve provavelmente ao fato de que o POLST não foi criado como um instrumento de pesquisa epidemiológica,

mas como um instrumento pragmático voltado para documentação de preferências de cuidado no fim da vida.

# *Objetivos gerais*

## OBJETIVOS GERAIS

Tendo em vista os argumentos apresentados acima e com o objetivo de produzir dados que subsidiem a futura utilização do POLST no Brasil a presente pesquisa pretende avaliar as propriedades psicométricas desse instrumento de acordo com as orientações técnicas do referencial COSMIN (*Consensus-based Standards for the selection of health Measurement Instruments)*, as quais contemplam: “Confiabilidade Interobservadores” e a “Validade de Construto” do formulário POLST adaptado para o Brasil.

# Resultados

## RESULTADOS

Os resultados seguem apresentados em forma de dois artigos, que contemplam os objetivos propostos.

O primeiro artigo, intitulado: ***"*Evaluation of the Interrater Reliability of End-of-Life Medical Orders in the Physician Orders for Life-Sustaining Treatment Form*"***, o qual foi publicado na *JAMA Network Open* em abril de 2019[28].

O segundo artigo, intitulado: ***"*To what extent do Physician Orders for Life-Sustaining Treatment (POLST) reflect patients' preferences for care at the end of life?*"***, aceito para publicação no Journal of the American Medical Directors Association (JAMDA) em 11 de outubro de 2020.

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*Artigo 1*

# Evaluation of the Interrater Reliability of End-of-Life Medical Orders in the Physician Orders for Life-Sustaining Treatment Form


## ABSTRACT

**Context:** Despite its spread in much of the United States and increased international interest, the Physician Orders for Life-Sustaining Treatment (POLST) paradigm still lacks supporting evidence. The interrater reliability of the POLST form to translate patients' values and preferences into medical orders for care at the end of life remains to be studied.

**Objective:** To assess the interrater reliability of the medical orders documented in POLST forms.

**Methods:** This cross-sectional study was conducted in a public university hospital in southeastern Brazil. Two independent researchers interviewed the same patients or decision-making surrogates (n = 64) during a single episode of hospitalization within a time frame of 1 to 7 days. Eligible participants were hospitalized adults aged 21 years or older who were expected to remain hospitalized for at least 4 days and whose attending physician responded no to the question, Would I be surprised if this patient died in the next year? Data collection occurred between November 1, 2015, and September 20, 2016, and first data analyses were performed on October 3, 2016.

**Results:** Of the 64 participants interviewed in the study, 53 (83%) were patients and 11 (17%) were surrogates. Patients' mean (SD) age was 64 (14) years, and 35 patients (55%) and 8 surrogates (73%) were women. Overall, in 5 cases (8%), disagreement in at least 1 medical order for life-sustaining treatment was found in the POLST form, changing from the first interview to the second interview. The κ statistic for cardiopulmonary resuscitation was 0.92 (95%CI, 0.80-1.00); for level of medical intervention, 0.89 (95%CI, 0.76-1.00); and for artificially administered nutrition, 0.92 (95%CI, 0.83-1.00).

**Conclusions:** The high interrater reliability of the medical orders in POLST forms appears to offer further support for this advance care planning paradigm; in addition, the finding that this interrater reliability was not 100% underscores the need to ensure that patients or their surrogates have decision-making capacity and to confirm that the content of POLST forms accurately reflects patients' current treatment preferences.


**Keywords:** POLST. Inter-rater reliability. Advance care planning. Advance directives. Validation studies.

## 1 INTRODUCTION

The Physician Orders for Life-Sustaining Treatment (POLST) paradigm was created in Oregon in the early 1990s as a coordinated system to elicit, document, and communicate the preferences of patients regarding medical interventions at the end of life.[1,2] The POLST paradigm was developed with the ethical purpose of increasing the chances of patients' values and preferences being respected at the end of their lives by the provision of medical care that is consistent with their values. It is primarily intended for patients with limited life expectancy and translates patients' values and preferences of care into a document (the POLST form), which comprises a standardized set of medical orders concerning life-sustaining interventions. A systematic review of studies about POLST found evidence that preferences of care documented as medical orders in POLST forms are more likely to guide care at the end of life than traditional advance directives alone.[3] The "Dying in America" report by the Institute of Medicine recognized POLST as an important area of progress toward the provision of end-of-life care that is consistent with patients' values, and the report recommended the federal government to encourage US states to implement POLST programs.[4] Within the past decade, POLST has been instituted or is in the process of being implemented in 46 of the 50 states5 and has recently raised international interest as a means to promote advance care planning and respect of patients' values at the end of life.[6]

Despite the recognition of POLST's importance, there are several gaps in the evidence about POLST.[3,7] One major underappreciated evidence gap is the absence of studies assessing the interrater reliability of the POLST form to translate patients' values into medical orders. Assessment of this psychometric property of the POLST form is important because it indicates to what extent one can trust that different clinicians, following a similar advance care planning approach, would arrive at the same set of medical orders documented in a POLST form. Hence, we

designed the present study to assess the interrater reliability of the POLST form completion process to capture treatment preferences at the end of life.

## 2 METHODS

This cross-sectional study was approved by the ethics research committee of Botucatu Medical School. All participants (ie, patients or their surrogates) signed informed consent forms. Data collection occurred between November 1, 2015, and September 20, 2016, and first data analyses were performed on October 3, 2016.

This study was based on the Consensus-based Standards for the Selection of Health Measurement Instruments[8-10] and followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guideline[11] for cross-sectional studies and the Guidelines for Reporting Reliability and Agreement Studies (GRRAS) reporting guideline[12] for studies of reliability and agreement.

The study was conducted at a single public university hospital in southeastern Brazil. Two of our independent researchers (G.B.L., J.J.C.R., A.M.R., A.F.N., M.A.M., C.G.F.F., C.S.C., J.F.L.S., R.R., and E.I.O.V.) interviewed the same patients or decision-making surrogates during a single episode of hospitalization and within a time frame of 1 to 7 days. The choice of this short time frame was intended to minimize the chance of loss to follow-up and the probability that changes in the state of patient health or care could jeopardize the assessment of interrater reliability.

Patients were eligible for the study if they were aged 21 years or older, were inpatients at the study hospital, and were expected to remain hospitalized for at least 4 days and if 1 of their attending

physicians answered no to the following question: Would I be surprised if this patient died in the next year?[13] If a potentially eligible patient was found during the first interview not to have decision-making capacity but to have a surrogate, the surrogate was invited to participate in

the research. Decision-making capacity was determined using the following criteria as described by Appelbaum[14]: (1) ability to communicate a choice, (2) understanding of the information communicated, (3) appreciation for the current medical condition and the likely consequences of different treatment options, and (4) ability to provide a set of reasons for the choice based on personal values. The assessment of decision-making capacity was performed during each advance care planning interview in which interviewers presented patients with a set of clinical situations, treatment options, and possible outcomes and observed how patients dealt with the information given, asked questions, expressed choices, and relayed back their understanding and the reasons for their preferences. Exclusion criteria were (1) the unavailability of the patient to participate in the second interview (eg, because of hospital discharge) and (2) the report in the beginning of the second interview that major clinical or personal events had occurred between interviews that changed the patient's perspective on end-of-life care.

During the first interview, after patients or their surrogates had signed the consent form, the interviewers collected sociodemographic data on age, sex, race/ethnicity, years of schooling, religion, main diagnosis, Charlson comorbidity index,[15] and functional status. We used the Palliative Performance Scale (score range: 0%-100%, with 0% indicating death and 100% indicating total autonomy plus lack of active illness) to rate functional status.[16] After the interview, the interviewers collected clinical data from patients' medical records, including comorbidities and the principal diagnosis that led to hospital admission.

O One third-year medical student (C.S.C.), 3 fourth-year medical students (J.J.C.R., C.G.F.F., and A.F.N.), 3 interns (J.F.L.S., R.R., and A.M.R.), 1 internal medicine resident (M.A.M.), 1 psychiatrist (G.B.M.), and 1 geriatrician (E.I.O.V.) composed the team of interviewers. Interviewers were trained in the structured advance care planning conversation and in the completion of the POLST form. Training sessions were face to face and

interactive, took 1 to 1½hours each, and were provided in small groups or individually. The advance care planning conversation approach in which the interviewers were trained was based on the POLST conversation model produced by the Coalition for Compassionate Care of California.[17] The model consisted of the possibility of 3 standardized clinical events occurring in the patient's current functional state: cardiac arrest during an acute myocardial infarction, severe pneumonia with respiratory failure, and coma after a major stroke. Interviewers were trained to ask patients to confirm their understanding of the information and situations that were presented during the advance care planning conversation. Specifically, interviewers required patients to relay back their interpretation of the information and to explain the reasoning behind their care preferences and their understanding of the likely consequences of the implementation of their preferences.

Each interviewer participated in as many training sessions needed to be considered confident in conducting such a conversation within the role-play scenarios presented in each session. A specific competency checklist to assess interviewers' readiness to begin interviewing patients was not used; however, we required that both the trainer (E.I.O.V.) and the interviewer under training agreed on the interviewer's readiness. The trainer focused specific attention on how interviewers framed situations, chose words, confirmed understanding, and recognized evidence of impaired decision-making capacity. Throughout the training sessions, the trainer pointed out how subtle wording choices could unduly persuade patients in a given direction. The minimum number of training sessions was 4 and the maximum was 10.

Interviewers who performed the second interview did not have access to the content of the first interview and were specifically instructed to avoid any conversation with patients about the first interview. Likewise, participants were instructed not to share with the second interviewer any aspect of the first interview because such behavior would jeopardize the research aims.

We used a POLST form that was recently cross-culturally adapted in Brazil[6] and was mostly based on the 2014 version of the POLST form from the state of Oregon. The Brazilian POLST form has 3 sections for documenting medical orders. Section A pertains to a situation in which the patient is found unresponsive, pulseless, and not breathing and indicates orders to attempt or not to attempt cardiopulmonary resuscitation (CPR). Section B pertains to the level of medical intervention to be provided if the patient has a pulse and is breathing: comfort measures only, limited treatment, or full treatment. Section C pertains to a situation in which the patient has difficulty with oral feeding and indicates orders to provide or not to provide, and for how long to provide, artificially administered nutrition: long-term nutrition by tube, defined trial period of artificial nutrition by tube, or no artificial nutrition by tube. Examples of POLST forms in the United States can be assessed elsewhere.[18,19] Note that the POLST form is not a questionnaire for patients to fill in which medical treatments they want. Instead, clinicians complete the POLST form according to 1 or more advance care planning conversations they have had with patients, taking into account the patients' preferences for care related to their current health condition.

### 2.1 Statistical analyses

Patients' demographic and clinical data were described through frequency tables. We described categorical data as absolute numbers and proportions and continuous data as mean and SD or median and interquartile range (IQR), as appropriate.

Statistical analyses follow the principles of classical test theory.[20] This theory was chosen for its simplicity and efficiency in terms of the sample size needs.[21] Moreover, some assumptions of the alternative paradigm, the item response theory, do not apply in the context of POLST, such as the local independence between items. To explore the factors associated with

the occurrence of disagreements between interviews, we used Fisher exact test when variables were categorical or Wilcoxon rank sum test when variables were continuous.[22]

We assessed interrater reliability using Cohen κ for section A of the POLST form, in which only 2 possibilities of responses exist (ie, attempt or do not attempt CPR), and weighted κ statistic for sections B and C, in which 3 possibilities of answers were given, ranging from less invasive to more invasive treatment options.[23] We adopted linear weighting as the method for the weighted κ statistic as defined a priori in the study protocol because that strategy was associated with greater simplicity of interpretation.[24] Nevertheless, following Ben-David's[25] recommendation, we performed a sensitivity analysis through the adoption of quadratic weighting to evaluate the robustness of the analyses.

We adopted α = .05 to indicate statistical significance. We used the R software, version 3.3.3 (R Foundation for Statistical Computing)26 for all statistical analyses.

### 2.2 Sample Size

We calculated a minimum sample size of 62 participants using the methodology proposed by Rotondi and Donner.[27] For this calculation, we considered the following guidelines:

1) distribution of marginal proportions in section B of the POLST form of 40% patient preference for comfort measures only, 49% for limited treatment, and 11% for full treatment (we derived these proportions from Hickman et al. [28]);

2) values of 0.75 as the lower limit and 0.99 as the upper limit of the 95%CI for the κ statistic;

3) estimated κ value of 90%;

4) presence of 2 interviewers; and

5) α = .05 for statistical significance.

## 3 RESULTS

We included 64 participants in the study, 53 (83%) of whom were patients and 11 (17%) of whom were surrogates. Thirty-five patients (55%) and 8 surrogates (73%) were women. Ten surrogates were children of patients, and only 1 surrogate was a patient's wife. The Figure 1 shows the flow diagram of participants. The mean (SD) interval of time between interviews was 2 (1.9) days.

The mean (SD) age of patients was 64 (14) years, and most patients (46 [72%]) self-identified as white and Catholic (40 [62%]). The median (IQR) Charlson comorbidity index was 3 (2-4), and the median (IQR) value for the Palliative Performance Scale was 80% (60%-90%). Further data on the clinical and sociodemographic profiles of patients are shown in Table 1.

Overall, differences were found in the recorded orders concerning at least 1 section of the POLST form for 5 (8%) of the 64 patients. For 1 participant, the CPR orders changed from the first interview to the second interview. Another participant had discordant orders for CPR and artificial nutrition between the 2 interviews. For 2 participants, the orders for medical interventions and nutrition were different, and for another participant the orders for nutrition changed between the 2 interviews. Table 2 and eTable 1 in the Supplement provide further details regarding the cases of agreement and disagreement between the 2 interviews according to each section of the POLST form.

The κ statistics assessing the interrater reliability for each section of the POLST form were high and are presented with their 95%CIs in Table 3. The κ statistic for CPR was 0.92 (95%CI, 0.80-1.00), for level of medical intervention was 0.89 (95%CI, 0.76-1.00), and for artificially administered nutrition was 0.92 (95%CI, 0.83-1.00).

We performed an exploratory comparison of baseline patient characteristics between cases in which at least 1 disagreement in orders between interviews was observed and cases in which complete agreement

was found between interviews (eTable 2 in the Supplement). The only statistically significant association we found between patients in those groups involved religion, in which Catholic and Evangelical patients had a smaller proportion of disagreement between interviews compared with patients who were Buddhist, were Spiritist, or reported no religion.

The sensitivity analysis of the weighted κ statistic that used quadratic weighting for sections B and C revealed a κ value of 0.90 (95%CI, 0.79-1.00) for section B and 0.94 (95%CI, 0.88-1.00) for section C.

## 4 DISCUSSION

To our knowledge, this study is the first to assess the interrater reliability of the POLST form completion process after a standardized advance care planning conversation anywhere in the world. The results point toward a high interrater reliability of the POLST paradigm to translate patients' preferences of care at the end of life into a set of medical orders for life-sustaining treatments. These results are important because they provide evidence supporting the POLST paradigm, which has spread across the United States and has raised interest internationally as a means to promote advance care planning and respect for patients' values at the end of life.[6]

However, despite the high interrater reliability we found for each section of the POLST form, we found 5 cases of disagreement between the outcomes of the 2 interviews. With regard to the discordance observed in sections B and C of the POLST form, for which there were 3 treatment options representing different degrees of life-sustaining interventions, none of the discordances involved comfort measures in one interview and full treatment in the other. Still, it is certainly disconcerting to find any cases of disagreement for medical orders for life-sustaining treatments within a very short time period. Those disagreements occurred despite our attempts to exclude patients who did not have decision-making capacity or who reported

having experienced major clinical or personal events between interviews that changed their perspectives on end-of-life care. Unfortunately, the available data do not make it possible to ascertain with confidence the reasons for those disagreements. The exploratory finding that Catholic and Evangelical patients had less frequent disagreements between interviews than patients who were Buddhist, were Spiritist, or reported no religion must be regarded with great caution because of the low numbers of individuals in the latter categories and the possibility of false-positive associations when conducting multiple statistical tests.[29] The religious views of patients have been shown to affect their treatment preferences at the end of life, but we could not find studies of the association between religious beliefs and the interrater reliability of instruments used to assess those preferences in a recent systematic review about religious beliefs and major end-of-life issues.[30]

A few hypotheses may explain the cases of disagreement. First, determining decision-making capacity can require some subjective interpretation of its elements, and some patients might not have fulfilled each criterion of that capability during both interviews. A review of 15 instruments used to assess treatment-related decision-making capacity found that the interrater reliability of these instruments was imperfect, with κ values ranging from 0.44 to 0.83.31 Second, participants might not have had a consistent opinion about care preferences and changed their minds between the interviews. We believe that the study interviews might have been the first time some participants were asked to consider issues concerning life-sustaining treatments. Third, the interviewers had not been involved with the care of the patients, which could have compromised their ability to identify some subtle inconsistencies in patients' preferences. Fourth, even though the interviewers were trained in a standardized advance care planning conversation, subtle differences in the way they communicated with participants could have affected the way participants responded to the questions. Fifth, although we generally believe that

humans make decisions by rationally weighing risks and rewards, we also believe that reasoning, thoughts, feelings, and decisions are affected by myriad subtle environmental and internal factors of which we are mostly unaware and that sometimes even render us unable to recognize that we have changed our minds.[32-34]

Hence, the 5 cases of disagreement in the POLST forms between the 2 interviews emphasize the importance of accurate assessment of decision-making capacity and indirectly support the concept that, ideally, advance care planning conversations should take place within an established patient-clinician relationship in which mutual trust and respect stem from previous experiences.[35] Ultimately, in real-life situations, such longitudinal relationships between patients, their surrogates, and clinicians are the most important warranty that the content of POLST forms accurately reflects patients' values and preferences of care. In addition, because miscommunication can occur even between clinicians and patients who have established relationships, the orders on a POLST form must be reviewed frequently to make sure they reflect the current preferences of the patient. In real life, patients receive a copy of their POLST form, representing another assurance that their values are reflected in those medical orders by allowing patients the opportunity to contemplate whether those orders are consistent with their current values. That patients or their surrogates can void POLST forms at any given moment represents yet another aspect of the POLST paradigm that may decrease the possibility of harm from medical orders that become inconsistent with patients' current preferences of care.

Few studies have assessed the interrater reliability of instruments that document advance care planning conversations. A Malaysian study evaluated the intrarater test-retest reliability of a locally developed questionnaire for assessing individuals' attitudes and awareness about advance care planning but not patients' preferences of care at the end of life.[36] The κ statistic for the items of that questionnaire ranged from 0.74 to 0.95. An Australian study evaluated the interrater reliability of an advance

care planning template documenting the care preferences and advance care plans of older adults in residential care facilities.[37] In the Australian study, 2 independent researchers interviewed 30 older adults within an unspecified period. The κ statistics ranged from 0.73 to 0.79, but no information was provided on the substance of disagreements in specific items of the advance care planning template that was used.

The study has some relevant implications for policy and practice. Although the high interrater reliability that we found offers support for the POLST paradigm, it was not 100% or perfect, highlighting the need to confirm the medical orders on a POLST form on subsequent patient interactions to make sure the orders accurately reflect the patients' current wishes. Future studies should assess other populations, conduct interviews with somewhat longer intervals of time, and compare preferences of care documented through POLST with different advance care planning strategies. Interrater reliability studies of other advance care planning documents in use are also much needed.

### 4.1 Limitations

This study has a number of limitations. First, the interval of time between the first and second interviews was short, which may have been associated with some degree of recall bias. Nevertheless, the optimum time interval between interviews for the assessment of interrater reliability depends on the population under study and the construct being measured. The ideal interval of time should not be so long that the construct under study might change but not so short that a recall bias is incurred. Because the population under study was composed of hospitalized patients with serious illnesses, long intervals of time would have been associated with the risk of patients undergoing clinical changes that could affect the construct being measured or of losing the patient from the study because of hospital discharge. Second, we studied a population of inpatients in a university

hospital in a middle-income country, which does not reflect other contexts in which POLST has been used. Most studies of POLST were conducted in long-term care facilities in the United States.[3] On the other hand, although the results may not be generalizable to other populations, they do contribute to the expansion of knowledge about POLST in previously understudied populations. Third, the interviewers were not assessed with a competency checklist to ensure they were adequately prepared to conduct advance care planning conversations. Fourth, despite the high level of interrater reliability that we identified, we cannot completely rule out the possibility that the content of POLST forms was not consistent with patients' actual values and preferences of care. An assessment of decision quality or the factors in specific treatment preferences was beyond the scope of this study.

## 5 CONCLUSIONS

This study appears to provide evidence of high interrater reliability of the POLST completion process, thereby offering further support for this innovative advance care planning paradigm. In addition, the finding that this interrater reliability was not 100% underscores the need to ensure that patients or their surrogates have the decision-making capacity to participate in advance care planning and that a process is in place to confirm that the recorded POLST orders accurately reflect patients' current treatment preferences.

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Figure 1 – Flow diagram of the study participants

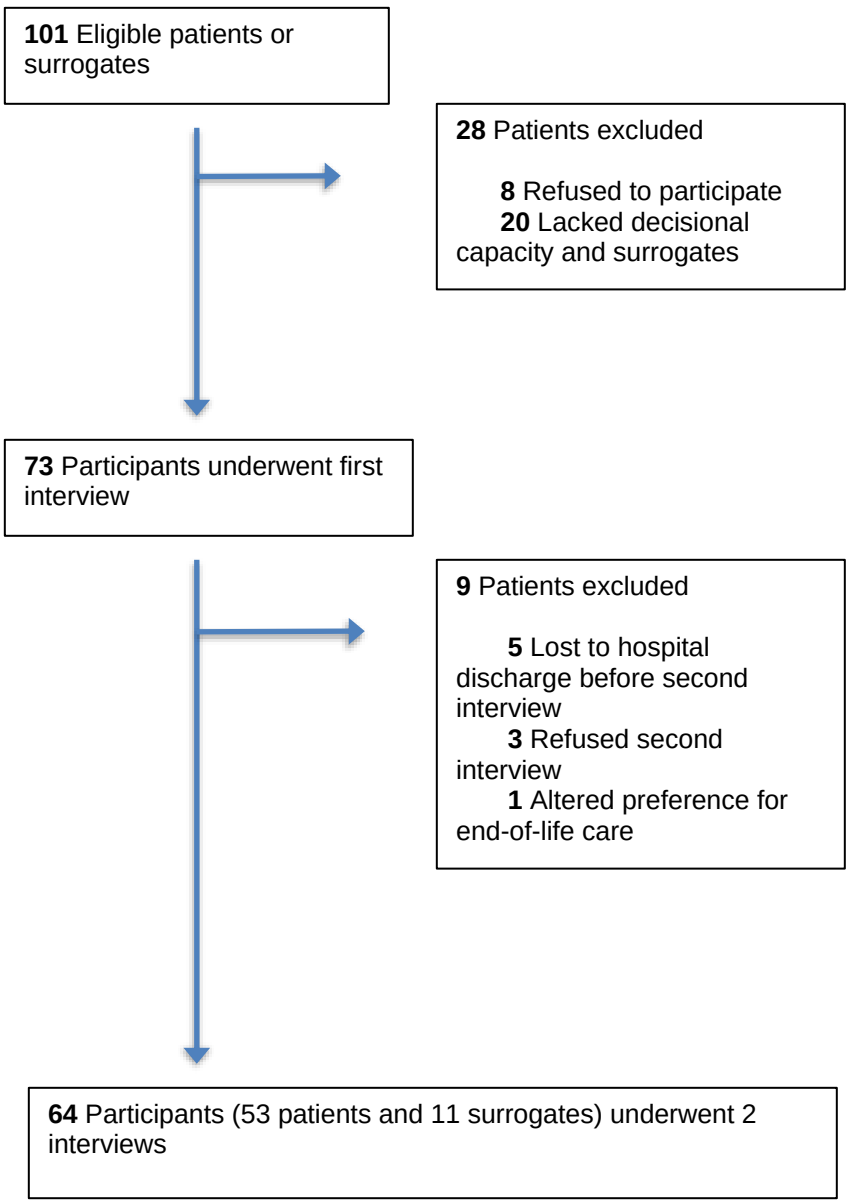

Table 1 - Clinical and sociodemographic profile of patients

| **Variable** | **Nº(%)** |
|---|---|
| Sex | |
| Female, N(%) | 35 (55) |
| Male, N(%) | 29 (45) |
| Age, mean (SD), y | 64 (14) |
| Race/Ethnicity | |
| Asian | 2 (3) |
| White | 46 (72) |
| Black | 16 (25) |
| Religion | |
| Buddhism | 2 (3) |
| Catholicism | 40 (62) |
| Spiritism | 2 (3) |
| Evangelicalism | 14 (23) |
| None reported | 6 (9) |
| Years of formal education completed, median (IQR) | 4.5 (4-10.5) |
| Illiterate | 2 (3) |
| Functionally illiterate[a] | 2 (3) |
| Interview performed with: | |
| Patient | 53 (83) |
| Surrogate | 11 (17) |
| Main diagnosis | |
| Cancer[b] | 38 (59) |
| Cardiovascular disease[c] | 12 (19) |
| Neurodegenerative disease[d] | 4 (6) |
| Other disorder[e] | 10 (16) |
| No. of diagnoses, median (IQR) | 3 (2.8-6) |
| Charlson comorbidity index[f] | |
| 0 | 1 (2) |
| 1 | 25 (39) |

| | |
|---|---|
| 2 | 21 (33) |
| 3 | 17 (27) |
| Palliative Performance Scale, median (IQR), %[g] | 80 (60-90) |

Abbreviation: IQR, interquartile range.

[a] Functional illiteracy was defined as ability to sign name but inability to read a journal or magazine article by self-report.

[b] Cancer included gastrointestinal, gynecological, breast, pulmonary, urological, and head and neck malignant neoplasms.

[c] Cardiovascular disease included chronic heart failure, coronary artery disease, and peripheral arterial disease.

[d] Neurodegenerative disease included Parkinson disease and dementia, such as Alzheimer disease and vascular dementia.

[e] Other disorder included frailty, hip fractures, liver failure, and other gastrointestinal disorders.

[f] Higher index means greater burden of comorbidities.

[g] Palliative Performance Scale score range: 0%-100%, with0%indicating death and 100% indicating total autonomy plus lack of active illness.

Table 2 - Summary of medical orders documented in the POLST and cases of disagreement between 2 interviews

| POLST Form Section | 1st Interview N(%) | 2nd Interview N(%) | Disagreement N(%) |
|---|---|---|---|
| **Section A**[a] | | | 2 (3) |
| Cardiopulmonary resuscitation | 48 (75)[b] | 48 (75)[b] | |
| Allow natural death | 16 (25)[b] | 16 (25)[b] | |
| **Section B**[c] | | | 2 (3)[b] |
| Comfort measures only | 0 | 1 (2) | |
| Limited treatment | 10 (16) | 10 (16) | |
| Full treatment | 54 (84) | 53 (83) | |
| **Section C**[d] | | | 4 (6) |
| Long-term nutrition by tube | 33 (52) | 30 (47) | |
| Defined trial period of artificial nutrition | 23 (37) | 25 (31) | |
| No artificial nutrition by tube | 8 (12) | 9 (14) | |

Abbreviation: POLST, Physician Orders for Life-Sustaining Treatment.

[a] Concerns situations in which patients are found unresponsive, pulseless, and not breathing, and the decisions involve performing cardiopulmonary resuscitation or allowing natural death.

[b] The proportions and absolute numbers are equal despite the presence of 2 cases of disagreement in medical orders between the 2 interviews because the same number of individuals had their preferences of care recorded in the opposite direction between interviews.

[c] Concerns any situation in which patients have a pulse and are breathing, and the decisions involve providing medical interventions in general.

[d] Concerns situations in which patients have difficulty with oral feeding, and the decisions involve providing enteral nutrition or not.

Table 3 – Raw interrater agreement and κ statistics for each section of the POLST form between the 2 interviews of 64 patients

| POLST Form Section | Raw interrater agreement, % | K Value (95% CI) | P Value |
|---|---|---|---|
| A. Cardiopulmonary resuscitation | 96.9 | 0.92 (0.80-1.00) | <.001 |
| B. Medical Interventions | 96.9 | 0.89 (0.76-1.00) | <.001 |
| C. Artificially administered nutrition | 93.8 | 0.92 (0.83-1.00) | <.001 |

CI: confidence interval.

Abbreviation: POLST, Physician Orders for Life-Sustaining Treatment.

## Supplementary eTables (e)

eTable 1 - Comparison of medical orders documented in Physician Orders for Life-Sustaining Treatment (POLST) forms from the 2 interviews in absolute numbers per individual participants (N = 64)

| **Section A: 2nd Interview** | | | |
|---|---|---|---|
| **Section A: 1st Interview** | | Attempt CPR | Do not attempt CPR |
| | Attempt CPR | 47 | 1 |
| | Do not attempt CPR | 1 | 15 |

| **Section B: 2nd Interview** | | | | |
|---|---|---|---|---|
| **Section B: 1st Interview** | | Comfort care only | Limited treatment | Full treatment |
| | Comfort care only | 0 | 0 | 0 |
| | Limited treatment | 1 | 9 | 0 |
| | Full treatment | 0 | 1 | 53 |

| **Section C: 2nd Interview** | | | | |
|---|---|---|---|---|
| **Section C: 1st Interview** | | Long-term artificial nutrition by tube | Defined trial period of artificial nutrition by tube | No artificial nutrition by tube |
| | Long-term artificial nutrition by tube | 30 | 3 | 0 |
| | Defined trial period of artificial nutrition by tube | 0 | 22 | 1 |

| | | | | |
|---|---|---|---|---|
| | No artificial nutrition by tube | 0 | 0 | 8 |

CPR: Cardiopulmonary resuscitation.

eTable 2 - A comparison of cases when there was at least one disagreement between interviews and cases when there was complete agreement between interviews (N = 64)

| **Patients' Characteristics** | **Any disagreement between interviews** | **Complete agreement between interviews** | **P** |
|---|---|---|---|
| Sex, N (%) | | | 0.17[a] |
| Female | 1 (2.9%) | 34 (86.2%) | |
| Male | 4 (97.1%) | 25 (13.8%) | |
| Age, mean (SD) | 66.7 (14.6) | 63.8 (13.9) | 0.80[b] |
| Ethnicity, N (%) | | | 0.10[a] |
| White | 4 (80.0%) | 42 (71.2%) | |
| Black | 0 (0%) | 16 (27.1%) | |
| Asian | 1 (20.0%) | 1 (1.7%) | |
| Religion, N (%) | | | 0.004[a] |
| Buddhism | 1 (20.0%) | 1 (1.7%) | |
| Catholicism | 1 (20.0%) | 39 (66.1%) | |
| Spiritism | 1 (20.0%) | 1 (1.7%) | |
| Evangelical | 0 (0%) | 14 (23.7%) | |
| No religion reported | 2 (40%) | 4 (6.8%) | |
| Years of formal education, median (IQR) | 4 (4 to 8) | 5 (4 to 11) | 0.70[c] |
| Literacy, N (%) | | | 1[a] |
| Literate | 5 (100%) | 55 (93.2%) | |
| Functionally illiterate | 0 (0%) | 2 (3.4%) | |
| Illiterate | 0 (0%) | 2 (3.4%) | |
| Interview performed with, N (%): | | | 1[a] |
| Patient | 4 (80.0%) | 49 (83.1%) | |
| Surrogate | 1 (20.0%) | 10 (16.9%) | |
| Charlson Comorbidity Index, N (%) | | | 0.21[a] |
| 0 | 0 (0%) | 1 (1.7%) | |
| 1 | 2 (40%) | 23 (39.0%) | |
| 2 | 0 (0%) | 21 (35.6%) | |

| | | | |
|---|---|---|---|
| 3 | 3 (20.0%) | 14 (23.7%) | |
| Main diagnosis, N (%) | | | 0.07[a] |
| Cancer | 1 (20.0%) | 37 (62.7%) | |
| Cardiovascular | 3 (60.0%) | 9 (15.3%) | |
| Neurological | 0 (0%) | 4 (6.8%) | |
| Other | 1 (20.0%) | 9 (15.3%) | |
| Number of diagnoses, median (IQR) | 6 (4 to 6) | 3 (2.5 to 6) | 0.27[c] |
| Palliative Performance Scale, median (IQR) | 70 (50 to 100) | 80 (60 to 90) | 0.94[c] |

[a] Fisher's test
[b] t test
[c] Wilcoxon rank sum test

*Artigo 2*

# TO WHAT EXTENT DO PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST) REFLECT PATIENTS' PREFERENCES FOR CARE AT THE END OF LIFE?


## ABSTRACT

**Objective:** To assess whether medical orders within POLST forms reflect patients' preferences for care at the end of life.

**Design:** This cross-sectional study assessed the agreement between medical orders in POLST forms and the free-form text documentation of an advance care planning conversation performed by an independent researcher during a single episode of hospitalization.

**Setting and Participants:** Inpatients at a single public university hospital, aged 21 years or older, and for whom one of their attending physicians provided a negative answer to the following question: "Would I be surprised if this patient died in the next year?"

**Measures:** Agreement between medical orders in POLST forms and the free-form text documentation of an advance care planning conversation was measured by Kappa statistics.

**Results:** Sixty-two patients were interviewed. Patients' median (Interquartile Range) age was 62 (56 to 70) years, and 21 patients (34%) were women. Overall, in 7 (11%) cases, disagreement in at least 1 medical order for life-sustaining treatment was found between POLST forms and the content of the independent advance care planning conversation. The Kappa statistic for cardiopulmonary resuscitation was 0.92 (95% CI: 0.82 to 1.00); for level of medical intervention, 0.90 (95% CI: 0.81 to 0.99); and for artificially administered nutrition, 0.87 (95% CI: 0.75 to 0.98).

**Conclusions and Implications:** The high level of agreement between medical orders in POLST forms and the documentation in an independent advance care planning conversation offers further support for the POLST paradigm. In addition, the finding that the agreement was not 100% underscores the need to confirm frequently that POLST medical orders accurately reflect patients' current values and preferences of care.


**Keywords:** POLST; validation studies; advance care planning; advance directives; palliative care

## 1 INTRODUCTION

The Physician Orders for Life-Sustaining Treatment (POLST) paradigm was created in the state of Oregon in the early 1990s as a coordinated system to elicit, document and communicate patients' preferences for medical interventions at the end of life.[1] Importantly, POLST differs from advance directives in a number of ways.[2] For example, it is intended exclusively for seriously ill or frail patients, focuses on patients' current state of health, and seeks to translate patients' values and preferences of care into a standardized set of medical orders concerning life-sustaining interventions. Indeed, the POLST form, a central piece of the POLST paradigm, takes the format of physician orders.

The "Dying in America" report by the Institute of Medicine in the USA recognized POLST as an innovation in care at the end of life consistent with patients' values, and recommended that states implement POLST programs.[3] Indeed, in Oregon POLST has been an important asset to change the landscape of end-of-life care.[4] Within the last decade POLST has been instituted or is in the process of being implemented in 46 of the 50 states in the USA[5] and has raised recent international interest as a means to promote advance care planning and respect for patients' values at the end of life in other countries.[6] Additionally, during the current COVID-19 pandemic POLST has received increasing attention as an important component of advance care planning strategies.[7,8]

A systematic review of POLST found evidence that medical orders in POLST forms are more likely to influence care at the end of life than advance directives alone and acknowledged the lack of studies assessing the quality of those medical orders as a critical knowledge gap deserving high priority in future studies[9]. Furthermore, few studies assessed the psychometric properties of the POLST form[10] and we are not aware of any study that addressed its construct validity. Therefore, the purpose of this study was to assess the construct validity of the POLST form by comparing medical

orders documented in POLST forms with the content of free-form documentation of an advance care planning conversation performed by an independent researcher.

## 2 METHODS

This cross-sectional study was conducted at a single public university hospital in Botucatu, SP, Brazil. Two independent researchers interviewed the same patient during a single hospitalization within a 7-day timeframe. This short timeframe was chosen to minimize loss to follow-up as well as the probability that changes in patients' health state would result in discordant preferences between interviews.

Patients were eligible for the study if they were aged 21 years or older, had decision-making capacity, were inpatients at the study hospital, were expected to remain hospitalized for at least 4 days and one of their attending physicians provided a negative answer to the following question: "Would I be surprised if this patient died in the next year?"[11] Decision-making capacity was determined using criteria described by Appelbaum.[12] Exclusion criteria involved 1) the unavailability of the research subject to participate in the second interview (e.g., because of hospital discharge) and 2) if research subjects reported in the beginning of the second interview that major clinical or personal events had occurred between interviews that changed their perspectives regarding end-of-life care.

During the first interview we collected socio-demographic data regarding age, sex, ethnicity, years of schooling, religion, main diagnosis, and functional status. We used the Palliative Performance Scale to rate functional status.[13] After the interview, researchers collected clinical data from patients' medical charts regarding current diagnoses to calculate the Charlson comorbidity index.[14]

One of the interviews was performed by a geriatrician / palliative care physician experienced in advance care planning who followed the approach

proposed by Sudore & Fried.[15] This approach entailed the identification of patients' preferred surrogate decision maker, the clarification of patients' values, and the determination of how much leeway patients were willing to grant their representatives regarding health-related decision-making (hereinafter called the Sudore-Fried approach to advance care planning). Iterative questions were used to explore previous experiences with illness dependence, and states of health patients would consider worse than death. The Sudore-Fried approach was chosen because, in the absence of a gold standard, it represented an internationally recognized strategy for advance care planning conversations that was not centered primarily around the presentation of specific clinical scenarios to patients, as was the conversational approach used in the other interview. The researcher performing the Sudore-Fried interview was instructed to attempt to cover patients' preferences of care regarding CPR, medical interventions such as the use of antibiotics, hospitalization, mechanical ventilation and artificial nutrition in the context of the interview, and to document free-text descriptions centered around patients' values so that the report could be a source of guidance for future in-the-moment medical decisions.

The second type of interview was based on an adapted version of a structured POLST conversation model developed by the Coalition for Compassionate Care of California[16] and was conducted individually by a researcher from our group, which included a fourth-year medical student, 6 interns, an internal medicine resident, and a psychiatrist. That advance care planning conversation was based on the presentation of 3 hypothetical clinical scenarios occurring in the patient's current state of health: 1) cardiac arrest, 2) severe pneumonia with respiratory failure, and 3) severe stroke with coma.

The group of "POLST interviewers" was trained in the structured advance care planning conversation and in the completion of POLST forms in face-to-face interactive 1 to 1.5-hour sessions that occurred in small groups or individually. Those interviewers were trained following the same

procedure described elsewhere.[10]

The 2 interviews did not follow any predefined order and the most important determinant for which interview was conducted first was the availability of time of the researchers responsible for each interview. Interviewers performing the second interview did not have access to the content of the first interview and were specifically instructed to avoid any conversation with patients about the first interview. Likewise, participants were instructed not to share with the second interviewer any aspect pertaining to the first interview because such behavior could jeopardize the research aims.

In this study we used a POLST form that was cross-culturally adapted to Brazil[6] and which was mostly based on the 2014 version of the Oregon POLST form. That form had 3 sections documenting medical orders: Section A which pertains to situations when patients are found unresponsive, pulseless and not breathing and includes orders to attempt or not to attempt CPR; Section B pertains to the level of medical intervention to be provided if the patient has a pulse and is breathing: “comfort measures only”, “limited treatment” and “full treatment” and also has a field for additional orders, in which clinicians can specify if patients have a preference for any treatment for a limited period of time or for those not on the POLST form such as dialysis; and Section C pertains to situations when patients have difficulty with oral feeding, and the orders address whether or not and for how long to provide artificially administered nutrition: “long-term nutrition by tube”, “defined trial period of artificial nutrition by tube” or “no artificial nutrition by tube.” Examples of POLST forms in the USA can be accessed elsewhere.[17,18] Importantly, the POLST form is not a questionnaire that is given to patients to fill in which medical treatments they want. Instead, authorized clinicians complete POLST forms based on one or several advance care planning conversations, taking into account patients’ preferences for treatment related to their current health condition.

The geriatrician/palliative care physician who performed the advance

care planning conversation using the Sudore-Fried approach documented that conversation in free-form text. Thereafter, an independent palliative care physician, who was also blinded to the content of POLST forms from study patients, analyzed the content of those texts and classified patients' preferences for life-sustaining treatments based on their current state of health regarding CPR, level of medical intervention and artificial nutrition using the same treatment options available in POLST forms. This procedure allowed a direct comparison with the corresponding sections of POLST forms completed by the other interviewer. Our *a priori* hypothesis to test for convergent validity was that the kappa statistics regarding those comparisons would be equal or superior to 0.75, because values at or above that cutoff are commonly considered evidence of excellent agreement.[19]

This project was approved by the local Institutional Review Board. All participants signed informed consent forms for the study. Data collection ocurred between October 2016 and September 2017.

This study was based on the *COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN).*[20–23] Besides the COSMIN guidelines, we also followed the STROBE[24] guidelines for cross-sectional studies and the GRRAS[25] guidelines for reporting studies of reliability and agreement.

### 2.1 Statistical analyses

Patients' demographic and clinical data were described with frequency tables. We described categorical data as absolute numbers and proportions, and continuous data as mean and standard deviation or median and interquartile ranges, as appropriate.[26]

To explore factors associated with the occurrence of disagreements between interviews we used Fisher's exact test or Wilcoxon's rank sum test when variables were categorical or continuous, respectively.[27]

We used Cohen's Kappa to assess agreement between interviews

for section A of the POLST form, in which only 2 possibilities exist (i.e., attempt or do not attempt CPR), and weighted kappa for sections B and C, in which more treatment possibilities were given, ranging from less invasive to more invasive treatment options.[28,29] We adopted linear weighting as the weighting method for the weighted Kappa statistic as defined *a priori* in our protocol because of the greater simplicity of interpretation associated with that strategy. Nevertheless, following Ben-David's recommendation[30] we performed a preplaned sensitivity analysis through the adoption of quadratic weighting parameters, as a way of evaluating the robustness of the analyses.

Patients with missing data regarding variables that were used directly for comparisons between the content of POLST forms and the classification of preferences of care based on the Sudore-Fried approach to advance care planning were excluded from the analyses that involved those variables.

We adopted 0.05 as the two-tailed alpha value for statistical significance. We used the R software version 3.6.2 (R Foundation for Statistical Computing, Vienna, Austria) for all statistical analyses.

## 2.2 Sample Size

We calculated a minimum sample size of 62 patients using the methodology proposed by Rotondi and Donner.[31] For that calculation we considered the following parameters:

- A distribution of marginal proportions regarding item B of the POLST form of 40%, 49% and 11% representing patient's preferences for medical interventions concerning comfort measures only, limited treatment and full treatment, respectively (we derived those proportions from Hickman et al.[32]
- The values of 0.75 and 0.99 as the lower and upper limits of the 95% confidence interval for the kappa statistic.
- An estimate of kappa of 90%.

- The presence of two evaluators.
- A two-tailed value for alpha of 0.05 for statistical significance.

## 3 RESULTS

We included 62 patients in the study, 41(66%) of whom were women. **Figure 1** shows the flow diagram of inclusion of participants. The median (IQR) interval of time between interviews was 2 days (1-2). The median (IQR) age of patients was 62 (56 to 70) years and 50 (81%) were white. Most patients were Catholic (36 [58%]) or of an evangelical religious background (20 [32%]). The median (IQR) Charlson Comorbidity Index was 3 (2-4) and the median (IQR) value for the Palliative Performance Scale was 70% (50%-80%). Further data on the clinical and socio-demographic profile of patients are shown in **Table 1**.

Figure 1 - Flow diagram of the inclusion of participants in the study

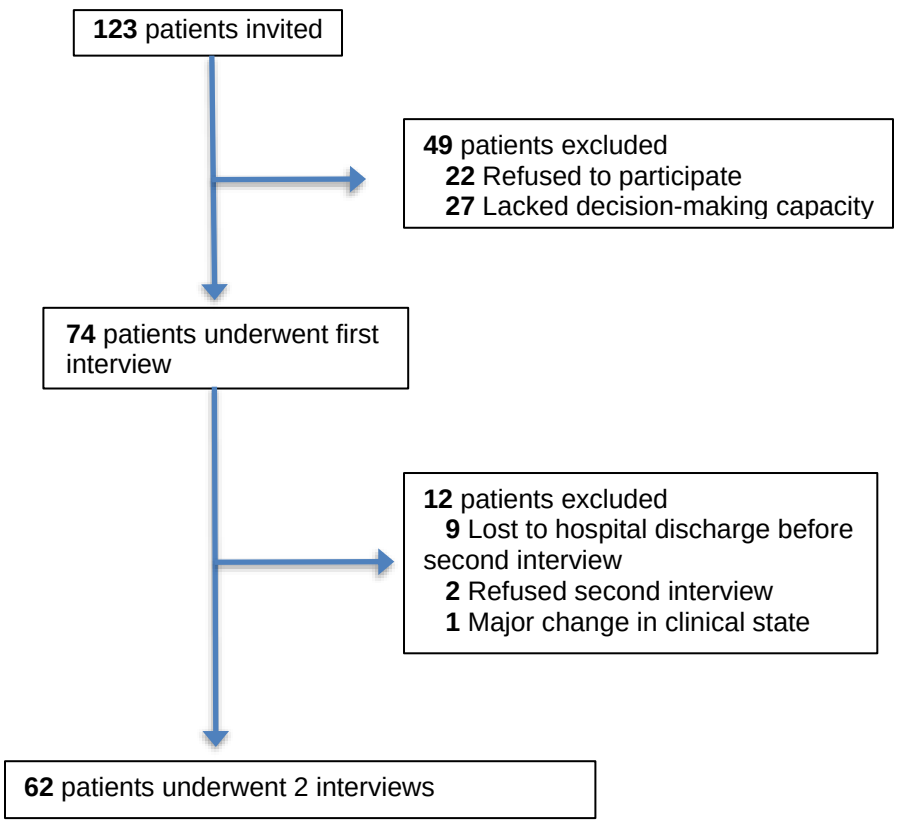

Table 1 - Clinical and sociodemographic profile of patients (N = 62)

| **Characteristics** | **N (%)** |
|---|---|
| Sex | |
| Female | 21 (34) |
| Male | 41 (66) |
| Age, median (IQR), y | 62 (56 to 70) |
| Ethnicity | |
| Asian | 3 (5) |
| White | 50 (81) |
| Black | 9 (15) |
| Religion | |
| Catholicism | 36 (58) |
| Spiritism | 2 (3) |
| Evangelicalism | 20 (32) |
| Christian, otherwise not specified | 2 (3) |
| No religion reported | 2 (3) |
| Years of formal education, median (IQR) | 5 (4 to 11) |
| Illiterate | 2 (3) |
| Functionally Illiterate * | 5 (8) |
| Main Diagnosis | |
| Cancer † | 24 (39) |
| Cardiovascular diseases ‡ | 16 (26) |
| Gastrointestinal diseases § | 10 (16) |
| Other ‖ | 12 (19) |
| Charlson Comorbidity Index ** | |
| 0 | 3 (5) |
| 1 | 18 (29) |
| 2 | 23 (37) |
| 3 | 18 (29) |
| Number of diagnoses, median (IQR) | 4 (3 to 6) |
| Palliative Performance Scale ††, median (IQR) | 70 (50 to 80) |

* Functional illiteracy was defined as being able to sign his/her name but unable to read a journal or magazine article by self-report.

† Cancers included gastrointestinal, gynecologic, pulmonary, hematological, urological and skin malignancies.
‡ Cardiovascular diseases included: heart failure, coronary artery disease, and peripheral arterial disease.
§ Gastrointestinal diseases included: cirrhosis, pancreatic, biliary and colonic disorders
‖ Other disorders included frailty, diabetes, chronic kidney disease, hematological and rheumatologic disorders.
** Charlson Comorbidity Index: higher levels mean greater burden of comorbidities.
†† The Palliative Performance Scale ranges from 0% to 100%, where 0% represents death and 100% total autonomy plus lack of active illness.

There were 5 cases for whom it was not possible to determine patients' preferences of care regarding artificial nutrition based on the analysis of the free-form text of the advance care planning conversation.

Overall, there were discordances regarding at least one medical order documented in POLST forms for 7 (11%) of the 62 patients when we compared the content of the three sections of POLST forms with the classification of preferences regarding CPR, level of medical intervention and artificial nutrition based on the independent assessment of the free-form text documenting the Sudore-Fried advance care planning conversation. For 2 patients disagreements concerned both CPR and level of medical interventions; for 3 patient disagreements encompassed both level of medical intervention and artificial nutrition, and for the 2 remaining patients the discordance was only with respect to the artificial nutrition option. **Table 2** summarizes the medical orders documented in POLST forms, the classification of preferences of care according to the free-form text of the advance care planning conversation and the numbers of discordances between those evaluations.

Table 2 - Summary of medical orders documented in POLST forms and the classification of patients' preferences of care according to the content of the free-form text of the advance care planning interview based on the Sudore-Fried approach[12]

| POLST Form Section | POLST form N(%) | Free-form text N(%) | Disagreement N(%) |
|---|---|---|---|
| **Section A** | | | |
| Cardiopulmonary resuscitation | 43 (69) | 43 (69) * | 2 (3) * |
| Allow natural death | 19 (31) | 19 (31) * | |
| **Section B** | | | |
| Comfort measures only | 3 (5) | 3 (5) | 5 (8) |
| Limited treatment | 11 (18) | 11 (18) | |
| Full treatment for a limited period | 35 (56) | 34 (55) | |
| Full treatment for an unlimited period | 13 (21) | 14 (23) | |
| **Section C** | | | |
| Long-term nutrition by tube | 20 (32) | 18 (32) † | 5 (9) † |
| Defined trial period of artificial nutrition | 32 (52) | 32 (56) † | |
| No artificial nutrition by tube | 10 (16) | 7 (12) † | |

Section A: This section concerns situations when patients are found unresponsive, pulseless & not breathing and decisions involve performing cardiopulmonary resuscitation or allowing natural death.
Section B: This section concerns any situation where patients have a pulse and are breathing, and involve medical interventions in general.
Section C: This section concerns situations where patients have difficulty with oral feeding, and involve decisions concerning the performance of enteral nutrition or not.
* Proportions and absolute numbers are equal despite the presence of 2 cases of disagreement between the outcomes of the 2 interviews because, as shown in Supplementary Table 1, the same number of individuals had their preferences of care recorded in opposite direction between interviews.
† The denominator used for the calculation of those proportions was 57 instead of 62 because there were five cases for whom the researcher was not able to classify patients' preferences of care regarding artificial nutrition based on the content of the free-form text documenting the Sudore & Fried advance care planning conversation.
The kappa statistics assessing the agreement between those 2 assessments were high and are presented with their 95% CIs in Table 3. Supplementary Tables 1, 2, and 3 provide further details regarding the cases of agrément and disagreement according to each section of the POLST form. The quality and the extent of cases of disagreement can be recognized as the numbers outside the main diagonal descending from the upper left to the lower right corner of those Supplementary Tables.

The Kappa statistics assessing the agreement between those 2 assessments were high and are presented with their 95% CIs in **Table 3**. Supplementary eTables 1, 2 and 3 provide further details regarding the cases of agreement and disagreement according to each section of the POLST form. The quality and the extent of cases of disagreement can be recognized as the numbers outside the main diagonal descending from the upper left to the lower right corner of those Supplementary eTables.

Table 3 - Raw agreement and Kappa statistics for comparisons between medical orders documented in POLST forms and the classification of patients' preferences of care according to the content of the free-form text of the advance care planning interview based on the Sudore-Fried approach[12]

| POLST Form Section | Raw inter-rater agreement | Kappa (95% CI) | P |
|---|---|---|---|
| A. Cardiopulmonary resuscitation | 97% | 0.92 (0.82-1.00) | <0.001 |
| B. Medical Interventions | 92% | 0.90 (0.81-0.99)*,† | <0.001 |
| C. Artificially administered nutrition | 89% | 0.87 (0.75-0.98) *,‡ | <0.001 |

* Weighted Kappa statistic using linear weighting.

† The sensitivity analysis using quadratic weighting for medical interventions resulted in Kappa of 0.93 (95%CI: 0.87-1.00)

‡ The sensitivity analysis using quadratic weighting for artificial nutrition resulted in Kappa of 0.89 (95%CI: 0.80-0.99)

We performed an exploratory comparison of baseline patient characteristics between cases in which at least one disagreement was observed between the interviews and cases in which complete agreement was found (Supplementary eTable 4). None of the variables that we examined, including the order of the interviews, were found to be significant predictors of the occurrence of disagreement between the different documentations of the 2 interviews.

# 4 DISCUSSION

Value concordance, how well the treatment that a patient receives aligns with the patient's values and preferences, is a core element of decision quality.[33] A step in the process toward achieving high quality decisions is for the orders for medical treatment to reflect accurately patients' preferences. Our study provides evidence of concordance between POLST medical orders and medical record documentation of an advance care planning conversation using a different approach and performed by an independent interviewer. This finding is important because it confirms the construct validity of the POLST form, points towards the quality of medical orders documented therein and offers support for the POLST paradigm as a means to translate patients' preferences of care into an actionable set of medical orders. Our results strengthen the evidence base for the POLST paradigm, which may also contribute to its spread internationally as a means to promote care at the end of life that is consistent with patients' values and preferences.

Despite the high values of the kappa statistics that we found, our results have shown that the concordance between medical orders in POLST forms and the free-form text approach to documentation of advance care plans was not 100%, as would be desirable for any document that is intended to direct end-of-life treatment. Of all types of disagreement that we observed, discordances regarding CPR are likely the most critical because when facing decisions to initiate CPR or allow natural death for a given patient, healthcare professionals usually don't have enough time to gather more information and to consider other factors before committing to a treatment decision. Fortunately, disagreements about CPR were the least common in our sample and occurred in only 2 (3%) participants.

The most likely explanation for the 7 cases of disagreement between the 2 interviews is that each interview used a different approach for the advance care planning conversation, which may have triggered different

perspectives and responses by the participants to the questions posed during the interviews. This hypothesis is supported by studies in health care and behavioral economics that show that people's preferences and decisions are influenced by how questions are asked.[34,35] Another possibility to explain the cases of disagreement is that participants presented genuine instability or decisional conflict regarding their preferences of care. A systematic review of 59 studies assessing the stability of advance care planning choices has found that between 20% and 30% of patients change their minds regarding end-of-life treatment preferences over a period of time from 1 to 36 months.[36] However, those results are not directly comparable to ours, since the inclusion criteria for studies in that review specified that the assessments of end-of-life treatment preferences had to be separated by at least 1 week or by a change in clinical status, whereas our interviews were performed in less than one week and major clinical changes between interviews was one of our exclusion criteria.

Our finding of discordance is in line with other previous research. Hickman et al.[37] conducted a pilot study of 28 nursing home residents to assess the quality of POLST medical orders. Those authors found the following proportions of discordance: 7% regarding CPR, 18% concerning medical interventions, 21% involving antibiotics and 11% for artificial nutrition. In that study the content of POLST forms completed within the last 12 months (mean of 157 days) was compared with participant-stated current preferences as assessed by a researcher after reading each section of the POLST form out loud to a patient or a surrogate.

Our study has some relevant implications for policy and practice. The fact that the agreement between the documentation of the 2 advance care planning approaches was not 100% emphasizes the need to check for consistency between different advance care planning documents and to continually revisit and revise POLST orders to confirm that they accurately reflect patients' current preferences.

Importantly, a recent study that evaluated the interrater reliability of

the POLST completion process, despite having examined a different psychometric property, arrived at a similar conclusion.[10] Other authors have previously demonstrated that finding inconsistencies between different approaches to advance care planning represents a valuable opportunity to clarify patient's values and perspectives towards life-sustaining treatments.[34]

Our study has a few potential limitations. First, we were not able to ask patients to clarify reasons for discordances between the two approaches to advance care planning. Second, our sample was small and restricted to inpatients from a single university hospital in a middle-income country, which does not reflect other contexts where POLST has been used, as most studies about POLST were conducted in long-term care facilities in the USA[9]. Third, the training level of our researchers and the quality of advance care planning discussions performed within our study may differ from usual practice in several locations. Hence, our results may not be generalizable to other areas and populations. Nevertheless, our study expands the knowledge about POLST in understudied populations and provides evidence that advance care planning conversations performed even by trained undergraduate medical students and interns may attain substantial levels of agreement with interviews performed by a more experienced physician. Additionally, our sample size was appropriate to the main aim of our study and the confidence intervals of our outcomes (Kappa statistics) were relatively small and restricted to values at or above 0.75.

## 5 CONCLUSIONS AND IMPLICATIONS

Our results provide evidence supporting the POLST paradigm as a means to achieve value and preference concordance by translating patients' preferences of care into medical orders consistent with those preferences. In addition, the finding that the agreement between medical orders documented in POLST forms and the content of a free-form text

documentation of an advance care planning conversation using a different approach was not perfect highlights the need to confirm frequently that POLST medical orders accurately reflect patients' current values and preferences of care.

## 6 ACKNOWLEDGMENTS

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## Supplementary eTables (e)

eTable 1 - Comparison of medical orders documented in section A of POLST forms regarding CPR with the content of the free-form text of the advance care planning interview based on the model proposed by Sudore & Fried[12] (N=62)

| | | **Classification of patients' preferences of care regarding CPR according to the free-form text of the advance care planning interview based on the proposal of Sudore & Fried[12]** | |
|---|---|---|---|
| | | Attempt CPR | Do not attempt CPR |
| **POLST interview** | Attempt CPR | 42 | 1 |
| | Do not attempt CPR | 1 | 18 |

CPR: Cardiopulmonary resuscitation

eTable 2 - Comparison of medical orders documented in section B of POLST forms regarding level of medical interventions with the content of the free-form text of the advance care planning interview based on the model proposed by Sudore & Fried[12] (N=62)

| | | **Classification of patients' preferences of care regarding level of medical interventions according to the free-form text of the advance care planning interview based on the proposal of Sudore & Fried[12]** | | | |
|---|---|---|---|---|---|
| | | Comfort care only | Limited treatment | Full treatment for limited period | Full treatment for unlimited period |
| **POLST interview** | Comfort care only | 3 | 0 | 0 | 0 |
| | Limited treatment | 0 | 10 | 1 | 0 |
| | Full treatment for limited period | 0 | 1 | 32 | 2 |
| | Full treatment for unlimited period | 0 | 0 | 1 | 12 |

eTable 3 - Comparison of medical orders documented in section C of POLST forms regarding artificial nutrition with the content of the free-form text of the advance care planning interview based on the model proposed by Sudore & Fried[12] (N=57)[a]

| | | **Classification of patients' preferences of care regarding artificial nutrition according to the free-form text of the advance care planning interview based on the proposal of Sudore & Fried[12]** | | |
|---|---|---|---|---|
| | | Long-term artificial nutrition by tube | Defined trial period of artificial nutrition by tube | No artificial nutrition by tube |
| **POLST interview** | Long-term artificial nutrition by tube | 16 | 2 | 0 |
| | Defined trial period of artificial nutrition by tube | 2 | 29 | 0 |
| | No artificial nutrition by tube | 0 | 1 | 7 |

[a] The total number of subjects described in this table is 57 instead of 62 because we excluded 5 patients for whom it was not possible to infer with certainty what were their preferences of care regarding artificial nutrition based on the free-form text documenting the advance care planning conversation.

eTable 4 - Comparison of cases in which there was at least one disagreement between medical orders in POLST forms and the classification of patients' preferences of care according to the content of the free-form text of the advance care planning interview based on the model proposed by Sudore & Fried[12]

| **Patients' Characteristics** | **Disagreement between interviews, N (%)** | **Agreement between interviews, N (%)** | **P** |
|---|---|---|---|
| Sex | | | |
| Female | 3 (14) | 18 (86) | 0.68[a] |
| Male | 4 (10) | 37 (90) | |
| Age, median (IQR) | 65 (62-70) | 61 (54-69) | 0.30[b] |
| Ethnicity | | | |
| White | 6 (12) | 44 (88) | 1[a] |
| Non-whites | 1 (8) | 11 (92) | |
| Religion | | | |
| Catholicism | 4 (11) | 32 (89) | 0.85[a] |
| Evangelicalism | 3 (15) | 17 (85) | |
| Christian without specification | 0 | 2 (100) | |
| Spiritism | 0 | 2 (100) | |
| No religion reported | 0 | 2 (100) | |
| Years of formal education, median (IQR) | 4 (4-15) | 5 (4-11) | 0.68[b] |
| Literacy | | | |
| Literate | 5 (9) | 50 (91) | 0.18[a] |
| Functionally illiterate / illiterate | 2 (29) | 5 (71) | |
| Charlson Comorbidity Index | | | |
| 0 | 0 | 3 (100) | 0.24[a] |
| 1 | 0 | 18 (100) | |
| 2 | 4 (17) | 19 (83) | |
| 3 | 3 (17) | 15 (83) | |

| | | | |
|---|---|---|---|
| Main diagnosis | | | |
| Cancer | 4 (17) | 20 (83) | |
| Cardiovascular diseases | 1 (6) | 15 (94) | 0.54[a] |
| Gastrointestinal diseases | 0 | 10 (100) | |
| Other | 2 (17) | 10 (83) | |
| Number of diagnoses, median (IQR) | 5 (4 to 9) | 4 (3 to 6) | 0.39[b] |
| Palliative Performance Scale, median (IQR) | 50 (45 to 80) | 70 (50 to 80) | 0.37[b] |
| Type of interview performed first | | | |
| POLST interview | 0 | 13 (100) | 0.33[a] |
| Sudore-Fried interview | 7 (14) | 42 (86) | |

[a] Fisher's test.
[b] Wilcoxon rank sum test.

# *Apêndices*

APÊNDICE A – Termo de consentimento livre e esclarecido

## Termo de Consentimento Livre e Esclarecido

**ADAPTAÇÃO TRANSCULTURAL DO QUESTIONÁRIO POLST: PHYSICAN ORDERS FOR LIFE-SUSTAINING TREATMENT.**

Eu, _____, R.G: _____, declaro por meio deste termo que recebi o convite e concordei em participar da pesquisa intitulada acima desenvolvida pela Disciplina de Geriatria do Departamento de Clínica Médica da Universidade Estadual Paulista Júlio de Mesquita Filho (UNESP).

Fui informado (a) pelo pesquisador _____ de que este estudo é coordenado pelo Dr. Edison Iglesias de Oliveira Vidal, a quem poderei contatar / consultar a qualquer momento que julgar necessário através do telefone 14-38801171.

Afirmo que aceitei participar por minha própria vontade, sem receber qualquer incentivo financeiro e com a finalidade exclusiva de colaborar para com o sucesso da pesquisa.

Fui informado dos objetivos estritamente acadêmicos do estudo, que, em linhas gerais é o de adaptar e validar para a língua portuguesa falada no Brasil um questionário desenvolvido nos Estados Unidos sobre os tipos de tratamentos que as pessoas gostariam ou não de receber quando estivessem próximas ao fim da vida.

Entendi que serei entrevistado para responder a esse questionário por duas vezes, ou seja, em dois momentos, e com intervalos que vão depender do local no Hospital das Clínicas da UNESP de Botucatu, em que eu estiver recebendo cuidados médicos, conforme especificado abaixo:

Se eu estiver internado no Hospital das Clínicas o intervalo entre uma entrevista e outra será de até semana após a primeira entrevista.

Se eu estiver sendo atendido ou acompanhado em algum dos serviços ambulatoriais do Hospital das Clínicas o intervalo entre uma entrevista e outra será de uma a três semanas.

Entendi ainda que, as entrevistas serão realizadas por diferentes membros da equipe de pesquisadores desta pesquisa, ou seja, os pesquisadores da primeira entrevista não serão os mesmos da segunda entrevista, e que isso é necessário para que os objetivos da pesquisa sejam alcançados.

Compreendi que ao aceitar participar desta pesquisa não será realizada nenhuma modificação no tratamento usual proposto pelos médicos responsáveis pelo meu cuidado,

Estou ciente de que a participação nesta pesquisa envolve conversar com um profissional de saúde sobre como eu gostaria de ser cuidado caso estivesse próximo ao fim da minha vida. Embora muitos pacientes sintam-se reconfortados em poder conversar sobre este assunto, estou ciente de que este tipo de conversa também pode causar sensações de ansiedade ou pensamentos depressivos em alguns pacientes. Fui informado que se tais alterações virem a ocorrer poderei contatar a equipe da pesquisa que intermediará os cuidados relativos aos meus sintomas por meio de comunicação com meus médicos e com o serviço de psicologia do Hospital das Clínicas.

Fui assegurado de que todas as informações que vir a fornecer a esta pesquisa serão tratadas de modo confidencial e que o acesso e a análise dos dados coletados se farão apenas pela equipe envolvida no estudo. Apenas caso eu assim o solicite, os dados obtidos através da aplicação deste questionário serão disponibilizados à equipe médica responsável por meus cuidados.

Fui informado de que não será realizada nenhuma coleta de exames em função desta pesquisa, além daqueles já solicitados espontaneamente por meus médicos.

Estou ciente de que, caso eu tenha dúvida ou me sinta prejudicado (a), poderei contatar o pesquisador responsável, ou ainda o Comitê de Ética em Pesquisa da Faculdade de Medicina de Botucatu UNESP situado em Rubião Jr ou pelo telefone (14) 3880-1608.

Declaro que recebi uma cópia assinada deste Termo de Consentimento Livre e Esclarecido.

Botucatu, ____ de _____ de _____

Paciente:
_____

Representante do Paciente:
_____

Assinatura do pesquisador responsável:
_____

APÊNDICE B - Script de “conversa do POLST” para a pesquisa de Adaptação Tanscultural do formulário POLST: Physician Orders for Life-Sustaining Treatment

Inicie a “conversa do POLST” seguindo os elementos principais do seguinte exemplo:

*“Gostaria de novamente lhe agradecer por ter aceito participar dessa pesquisa. Como eu expliquei antes, o objetivo dessa conversa é tentar entender como as pessoas gostariam de ser cuidadas caso alguns problemas de saúde acontecessem de repente e os pacientes não conseguissem se comunicar e explicar para os médicos que tipo de coisas eles gostariam que os médicos fizessem ou deixassem de fazer para ajudá-los. Então nós vamos fazer um exercício de imaginação em que eu vou pedir para o(a) Sr(a) se imaginar em algumas situações como se elas fossem acontecer de repente, hoje à noite por exemplo. É importante que o(a) Sr(a) saiba que eu não acho que nenhuma das coisas que eu vou pedir para o(a) Sr(a) imaginar irão de fato ocorrer hoje à noite ou nos próximos dias, mas que eu espero que o exercício de imaginá-las me ajude a entender as coisas que são importantes para o(a) Sr(a) e como o(a) Sr(a) gostaria de ser cuidado caso elas acontecessem. Isso é importante porque nós acreditamos que as pessoas devem ser cuidadas da forma como elas acham mais adequado, sem deixar de fazer as coisas que elas gostariam que fossem feitas, e sem fazer coisas que elas não gostariam que fossem feitas.”*

Observação Importante:
Durante a conversa do POLST esteja atento às emoções e reações do paciente ou da família:

- Permita tempo para silêncio.
- Dê tempo para suas reações.
- Convide a fazerem perguntas.
- Busque confirmar a compreensão do paciente.

**Continue a conversa do POLST (POLST Seção A):**

*“Eu gostaria então que o(a) Sr(a) imaginasse que o(a) Sr(a) está do jeito que o o(a) Sr(a) está agora e de repente o seu coração parou de bater por causa de um infarto do coração. Quando o coração parou de bater, isso quer dizer que o(a) Sr(a) estaria morrendo, parando de respirar para não acordar mais.*

*Quando isso acontece com um paciente os médicos podem tentar fazer o coração voltar a bater ou podem deixar o paciente ter uma morte natural.*
*Para tentar fazer o coração voltar a bater os médicos fazem aquelas coisas que aparecem nos filmes, quer dizer, dar choque no peito, fazer compressões no peito e podem até colocar a pessoa para respirar com ajuda de uma máquina, através de um tubo que é passado pela garganta do paciente. Essas coisas que os médicos podem fazer para tentar fazer o coração voltar a bater e para não deixar a pessoa morrer são chamadas de Ressuscitação Cardiopulmonar, ou RCP.*
*É importante saber que grande parte das pessoas que são submetidas a esses procedimentos para tentar fazer o coração voltar a bater não sobrevivem, principalmente se há uma grande demora até que a RCP seja iniciada, se os pacientes já são muito idosos ou já estão muito doentes por causa de vários problemas de saúde. De forma geral, pessoas idosas com múltiplos problemas de saúde ou dificuldade em tomar conta de si mesmo, têm menos de 1% de chance de viver depois de uma RCP. Mesmo para uma pessoa relativamente saudável em uma e em uma instituição de saúde bem preparada para reabilitação de curto prazo, se essa pessoa sobreviver à RCP, menos de 10% estão vivas depois de 60 dias. Outro problema tem a ver com quanto tempo o coração ficou parado e quanto tempo o cérebro ficou sem receber oxigênio enquanto o coração estava parado e o sangue não estava circulando pelo corpo. Isso é importante porque se o cérebro fica sem oxigênio por muito mais que 5 minutos há uma grande chance de que o cérebro sofra danos importantes e até mesmo que a pessoa, mesmo que o coração volte a bater, fique incapaz de se cuidar e fique em uma cama sem conseguir se comunicar com as outras pessoas, tendo de usar fraldas e dependente dos outros para tudo. Essa situação é chamada de estado vegetativo.*
*Acontece que eu tenho pacientes diferentes, que pensam coisas diferentes e que gostariam de ser cuidados de formas diferentes. Alguns dos meus pacientes gostariam que numa situação como aquela em que o coração de repente parou de bater e eles estão morrendo, que os médicos e a equipe de saúde tentassem fazer o coração voltar a bater a todo o custo independente da chance do coração voltar a bater e do risco de ficar em estado vegetativo.*
*Mas eu também tenho pacientes que pensam o contrário. Eles pensam que se o coração deles parasse de bater de repente, eles gostariam que os médicos lhes deixassem ter uma morte natural e não fizessem aquelas coisas para fazer o coração voltar a bater.*
*Eu sei que falei muitas coisas. Tem alguma coisa que eu falei que não ficou clara para o(a) Sr(a)? Tem alguma pergunta que o(a) Sr(a) gostaria de me fazer?*
*O que o(a) Sr(a) pensa sobre tudo isso que eu acabei de falar? O(a) Sr(a) sente que se parece mais com que tipo de paciente? Por quê?"*

É fundamental prestar toda atenção nas respostas do paciente. Não basta anotar que o paciente quer RCP ou uma morte natural. É essencial entender os valores e motivos que embasam o posicionamento do paciente.
A partir da compreensão sobre os valores do paciente que embasam seu posicionamento você deve traduzir para o paciente sua interpretação e como isso se transformaria em uma prescrição médica no formulário.

*"Então, se eu entendi corretamente o que o(a) Sr(a) acabou de me falar, se o coração do(a) Sr(a) parasse de bater de repente o(a) Sr(a) gostaria que os médicos (tentassem fazer o coração voltar a bater) / (deixassem o(a) Sr(a) ter uma morte natural) porque o(a) Sr(a) acredita que (explicitar os valores reportados pelo paciente). Ok, então eu vou anotar aqui que, se por acaso seu coração parasse de bater de repente, os médicos deveriam fazer assim. Novamente quero reforçar que eu não acho que isso vai acontecer hoje à noite nem nos próximos dias, Ok?"*

Se a opção para a seção A do formulário POLST foi por "Permitir Morte Natural / Não tentar RCP", marque essa opção e vá para a seção B.
Se a opção para a seção A for "Tentar ressuscitação / RCP" marque essa opção na seção A e logo em seguida marque na seção B a opção "Tratamento Invasivo Completo". Então siga o exemplo a seguir.

**POLST Seção B: Intervenções Médicas (para pacientes que gostariam de receber RCP na seção A)**

*"Agora vamos continuar com nosso exercício de imaginação e imaginar que o os médicos conseguiram fazer o seu coração voltar a bater, mas que apesar de isso ter ocorrido que o(a) Sr(a) precisou ir para a UTI, porque depois que o coração voltou a bater o(a) Sr(a) não acordou e continuou precisando da ajuda de uma máquina para respirar através de um tubo na garganta que leva o ar para os pulmões. Vamos agora imaginar que os dias estão passando e que ao invés de melhorar o(a) Sr(a) está piorando, não está acordando e os médicos acreditam que seria muito improvável, praticamente impossível, que o(a) Sr(a) venha a conseguir voltar a se comunicar com as outras pessoas e viver sem o uso de máquinas para ajudar o(a) Sr(a) a respirar.*
*Numa situação como essa, existem pessoas que dizem que elas não gostariam de ter sua vida prolongada se a chance delas voltarem a se comunicar com outras pessoas fosse muito pequena, praticamente impossível. Essas pessoas pensam que deram uma chance à vida tentando a RCP para fazer o coração voltar a bater, mas que não valeria a pena serem mantidas vivas às custas de aparelhos caso praticamente não*

*houvesse chance de voltarem a se comunicar com outras pessoas.*
*Por outro lado, também existem pessoas que pensam de forma diferente. Essas pessoas gostariam de ser mantidas vivas mesmo que à custa do uso de aparelhos, como as máquinas de respiração mecânica que jogam o ar para dentro dos pulmões das pessoas que não conseguem respirar sozinhas. Para esses pacientes valeria a pena ser mantido vivo desse jeito mesmo que a chance de voltar a conseguir se comunicar com as outras pessoas seja mínima.*
*Eu sei que falei muitas coisas. Tem alguma coisa que eu falei que não ficou clara para o(a) Sr(a)? Tem alguma pergunta que o(a) Sr(a) gostaria de me fazer?*
*Antes de perguntar a(o) Sr(a) o que pensa sobre essa situação, gostaria de lhe pedir para tentar me explicar com suas próprias palavras o que o(a) Sr(a) entendeu sobre essa situação que eu acabei de lhe explicar, para que eu possa confirmar se fui claro.*

*O que o(a) Sr(a) pensa sobre tudo isso que eu acabei de falar? O(a) Sr(a) sente que se parece mais com que tipo de paciente? Por quê?"*

Novamente, é fundamental prestar toda atenção nas respostas do paciente. É essencial entender os valores e motivos que embasam o posicionamento do paciente.
A partir da compreensão sobre os valores do paciente que fundamentam seu posicionamento você deve traduzir para o paciente sua interpretação e como isso se transformaria em uma prescrição médica no formulário.

*"Então, se eu entendi corretamente o que o(a) Sr(a) acabou de me falar, se o o(a) Sr(a) se encontrasse em uma situação em que a única forma de mantê-lo(a) vivo(a) fosse através do uso de aparelhos, como máquinas de respirar, e as chances de o senhor recobrar a capacidade de se comunicar com as outras pessoas fosse mínima, o(a) Sr(a) gostaria que os médicos (não prolonguem sua vida à custa de aparelhos e permitissem que o(a) Sr(a) tivesse uma morte natural) / (mantivessem os esforços para mantê-lo(a) vivo, ainda que através do uso de aparelhos), porque o(a) Sr(a) acredita que (explicitar os valores reportados pelo paciente). Ok, então eu vou anotar aqui quem se por acaso isso ocorresse, os médicos deveriam fazer assim. Novamente quero reforçar que eu não acho que isso vai acontecer hoje à noite nem nos próximos dias, Ok?"*

De acordo com a resposta do paciente você deve preencher o campo sobre instruções adicionais da seção B do formulário com uma observação que expresse em linhas gerais: a) O paciente não gostaria de ser mantido vivo artificialmente por período indeterminado caso as chances de recuperar sua capacidade de comunicação sejam mínimas; **ou** b) O paciente gostaria de ser mantido vivo artificialmente

por período indeterminado ainda que as chances de recuperar sua capacidade de comunicação sejam mínimas.

**POLST Seção B: Intervenções Médicas (para pacientes que não desejam receber RCP na seção A)**

Para os pacientes a quem na seção A foi marcada a opção "**Permitir Morte Natural / Não tentar ressuscitação**" continue com a Seção B da seguinte forma:

*"Agora vamos fazer um segundo exercício de imaginação. Dessa vez eu gostaria que o(a) Sr(a) imaginasse que o(a) Sr(a) estava do jeito que está agora, mas que de repente começou a se sentir mais cansado e apresentar tosse. No início parecia ser apenas uma gripe mas ao invés de melhorar com o passar dos dias o(a) Sr(a) foi piorando cada vez mais, ficando com muita falta de ar e ficando confuso. Quando os médicos avaliam o(a) Sr(a) eles descobrem que o(a) Sr(a) está com uma pneumonia pegando os dois pulmões e que essa é uma pneumonia muito grave e que está dificultando a sua respiração.*
*Quando um paciente tem uma pneumonia tão grave a ponto de dificultar muito sua respiração, uma das coisas que os médicos podem fazer é dar remédios para sedar o paciente, ou seja para fazer o paciente dormir profundamente, e colocar o paciente para respirar com a ajuda de uma máquina, através de um tubo que é colocado na garganta do paciente e empurra o ar para dentro dos pulmões do paciente. Quando a respiração do paciente está muito fraca, a passagem desse tubo pela garganta e que fica ligado na máquina de respiração representa a melhor chance de manter o paciente vivo. Normalmente os pacientes que estão usando esses aparelhos para respirar são cuidados nas UTIs, Unidades de Terapia Intensiva, onde a família não costuma poder ficar o tempo todo ao lado do paciente. Também é importante que o(a) Sr(a) saiba que esse tipo de tratamento costuma ser desconfortável porque o tubo pode incomodar a garganta do paciente, usualmente é necessário aspirar secreções do tubo – o que faz os pacientes tossirem muito – e também muitas vezes é necessário amarrar as mãos dos pacientes para impedir que eles puxem o tubo ou que o tubo saia do lugar. Apesar disso, quero que o(a) Sr(a) saiba que todos os esforços são feitos para minimizar esses incômodos e que a maior parte do tempo os pacientes ficam sedados, quer dizer dormindo com o uso de remédios e não percebem nem se recordam desses desconfortos. Quando as pessoas são fortes e tem poucos problemas de saúde, na maioria das vezes elas conseguem melhorar em alguns dias e voltam a respirar sem a necessidade de máquinas de respiração. Mas quando as pessoas já estão muito fracas ou possuem muitos problemas graves de saúde, muitas vezes é muito mais difícil voltar a conseguir respirar sozinho sem a máquina. Além disso, muitos pacientes ficam confusos durante o período em que ficam na UTI e em uso da respiração mecânica.*

*Usualmente, os pacientes saem mais fracos das UTIs e da ventilação mecânica e sua capacidade de realizar suas atividades depois da alta costuma ser menor do que aqueles que possuíam antes de desenvolverem a pneumonia. O grau de recuperação dos pacientes após uma passagem pela UTI com ventilação mecânica depende muito do estado de saúde do paciente antes desses eventos. Os pacientes mais fortes e mais saudáveis tem mais chance de recuperação plena que os pacientes mais fracos e com mais problemas de saúde.*
*Então, eu tenho pacientes diferentes e que pensam coisas diferentes sobre essa situação. Eu tenho pacientes que gostariam de ser submetidos à ventilação mecânica e de serem internados em uma UTI como uma forma de tentar continuar a viver e dar tempo para os antibióticos fazerem efeito contra a pneumonia.*
*Mas também existem pacientes que pensam que se, um dia estiverem com uma pneumonia, que eles gostariam que os médicos deixassem a doença seguir seu rumo natural, que iria levá-los à morte, e sequer gostariam que lhes dessem antibióticos para tratar a pneumonia; mas gostariam de todos os cuidados possíveis para mantê-los confortáveis, sem dor ou falta de ar, por exemplo, usando medicamentos que combatem a dor e a falta de ar mas não curam a pneumonia. Esses pacientes normalmente prefeririam ficar em suas casas ao invés de serem levados aos hospitais. Eles aceitariam ser tratados em hospitais apenas se não fosse possível mantê-los confortáveis em casa.*
*E também há pacientes que ficam no meio do caminho. Por um lado, eles não gostariam de ser submetidos à ventilação mecânica ou de ficar internados em uma UTI. Por outro lado, eles gostariam que, além das medidas de conforto para tratar dor e falta de ar que todos os pacientes devem receber, que os médicos tentassem trata-los com antibióticos e usassem remédios pelas vias necessárias (por exemplo, nas veias do braço ou do pescoço) e até mesmo máscaras de respirar, mas sem que colocassem tubos em suas gargantas para levar ar aos pulmões. Esses pacientes aceitariam ser tratados em hospitais se suas chances de sobreviver forem maiores sendo cuidados nesses locais.*
*Eu sei que falei muitas coisas. Tem alguma coisa que eu falei que não ficou clara para o(a) Sr(a)? Tem alguma pergunta que o(a) Sr(a) gostaria de me fazer?*
*Antes de perguntar a(o) Sr(a) o que pensa sobre essa situação, gostaria de lhe pedir para tentar me explicar com suas próprias palavras o que o(a) Sr(a) entendeu sobre essa situação que eu acabei de lhe explicar, para que eu possa confirmar se fui claro.*
*O que o(a) Sr(a) pensa sobre tudo isso que eu acabei de falar? O(a) Sr(a) sente que se parece mais com que tipo de paciente? Por quê?"*

Novamente, é fundamental prestar toda atenção nas respostas do paciente. É essencial entender os valores e motivos que embasam o posicionamento do paciente.

A partir da compreensão sobre os valores do paciente que fundamentam seu posicionamento você deve traduzir para o paciente sua interpretação e como isso se transformaria em uma prescrição médica no formulário.

*"Então, se eu entendi corretamente o que o(a) Sr(a) acabou de me falar, se o o(a) Sr(a) se encontrasse em uma situação como a de uma pneumonia grave com dificuldade para respirar, o(a) Sr(a) gostaria que (os médicos colocassem o o(a) Sr(a) em respiração mecânica em uma UTI) / (fizessem apenas medidas de conforto para tratar sintomas como dor e falta de ar mas não dessem antibióticos ou fizesse outras medidas para tentar prolongar sua vida) / (fizessem medidas como antibióticos, internação no hospital, remédios na veia e outras intervenções para tentar tratar a pneumonia e prolongar a sua vida, mas sem passar tubo de respiração na sua garganta ou colocá-lo(a) em uma UTI) porque o(a) Sr(a) acredita que (explicitar os valores reportados pelo paciente). Ok, então eu vou anotar aqui que se por acaso isso ocorresse, os médicos deveriam fazer assim. Novamente quero reforçar que eu não acho que isso vai acontecer hoje à noite nem nos próximos dias, Ok?"*

De acordo com a resposta do paciente você deve preencher a seção B do formulário com uma das opções: a) Somente Medidas de Conforto; b) Tratamento Limitado; ou c) Tratamento Invasivo Completo.
Para os pacientes aos quais for marcada a opção "Tratamento Invasivo Completo", o entrevistador deve proceder com o mesmo diálogo utilizado após o preenchimento da seção A para os pacientes cujas preferências de cuidado envolviam a realização de RCP, ou seja, de forma a preencher o campo de instruções adicionais da seção B, onde se determina as preferências dos pacientes quando à manutenção de medidas de suporte de vida por período indeterminado mesmo frente a um cenário de recuperação de capacidade de comunicação muito improvável.

**POLST Seção C: Nutrição Administrada Artificialmente**

*"Agora vamos fazer um último exercício de imaginação. Eu gostaria que o(a) Sr(a) imaginasse que teve um derrame / AVC grande e que ficou em coma, sem conseguir se comunicar, se mover ou comer. Quando uma pessoa tem um derrame muitas vezes os médicos não tem certeza quanto à possibilidade da pessoa se recuperar. De fato há pessoas que após algum tempo apresentam uma boa melhora dos déficits do derrame e outras pessoas que nunca se recuperam. A melhor forma de saber as chances de recuperação de uma pessoa após um derrame é observar a evolução dela ao longo do tempo.*
*Agora eu gostaria de conversar com o(a) Sr(a) sobre as possibilidades de alimentação numa situação como essas.*
*Quando uma pessoa está em coma ou passa a maior parte do tempo*

*desacordada, não é possível oferecer comida pela boca para essa pessoa, porque ela não conseguiria engolir nada direito.*
*De forma geral há três tipos de pacientes aqui. Alguns pacientes aceitariam usar uma sonda de alimentação artificial por período indefinido. Quer dizer que eles aceitariam receber sua alimentação por uma sonda para sempre se não conseguissem voltar a engolir normalmente.*
*O(a) Sr(a) já viu alguém usando uma sonda de alimentação artificial?*
*As sondas de alimentação de modo geral são tubos pequenos de borracha que podem passar pelo nariz e ir até o estômago ou podem ser inseridas diretamente na barriga para chegar ao estômago por um pequeno buraco que é feito na pele dos pacientes.*
*Como eu estava dizendo, há alguns pacientes que aceitariam receber comida por uma sonda de alimentação para sempre se não conseguissem recuperar a capacidade de comer pela boca e de se comunicar.*
*Por outro lado, também há alguns pacientes que não aceitariam receber comida por uma sonda de forma nenhuma e que prefeririam ficar sem comer nada se não pudessem comer pela boca, mesmo que eles fossem se desnutrir e isso aumentasse sua chance de morrer.*
*Finalmente, há alguns pacientes que estão no meio do caminho entre esses dois grupos: eles aceitariam ser alimentados através de uma sonda por um período de teste até os médicos terem maior clareza sobre suas possibilidades de recuperação da capacidade de se comunicar e de comer pela boca. Caso as chances de recuperação dessas capacidades seja muito improvável, eles prefeririam parar de ser alimentados pela sonda, mesmo que continuassem sem conseguir comer pela boca e que a falta de alimento os desnutrisse e aumentasse sua chance de morrer.*
*Antes de perguntar a(o) Sr(a) o que pensa sobre essa situação, gostaria de lhe pedir para tentar me explicar com suas próprias palavras o que o(a) Sr(a) entendeu sobre essa situação que eu acabei de lhe explicar, para que eu possa confirmar se fui claro.*
*Ótimo, agora que sei que o(a) Sr(a) me entendeu corretamente, gostaria que o(a) Sr(a) me dissesse o que pensa sobre essa situação. Com que grupo de pacientes o(a) Sr(a) acha que se parece mais? Por quê?"*

> Novamente, é fundamental prestar toda atenção nas respostas do paciente. É essencial entender os valores e motivos que embasam o posicionamento do paciente.
> A partir da compreensão sobre os valores do paciente que fundamentam seu posicionamento você deve traduzir para o paciente sua interpretação e como isso se transformaria em uma prescrição médica no formulário.

*"Então, se eu entendi corretamente o que o(a) Sr(a) acabou de me falar, se o o(a) Sr(a) se encontrasse em uma situação como a de um derrame em que o(a) Sr(a) não conseguisse engolir, que o(a) Sr(a) gostaria (que os médicos lhe oferecessem alimentação por sonda por período*

*indeterminado) / (de não receber alimentação por outra via que não fosse a boca, e preferiria inclusive ficar sem comer se não pudesse comer pela boca, sabendo que o(a) Sr(a) iria se desnutrir e que isso levaria à sua morte) / (que fosse feito um período de teste de alimentação por sonda até os médicos terem clareza sobre sua chance de voltar a engolir. Nesse caso, se essas chances forem muito pequenas e não for possível alimentar o(a) Sr(a) pela boca novamente sem lhe causar desconforto, o(a) Sr(a) preferiria ficar sem comer, sabendo que o(a) Sr(a) iria se desnutrir e que isso levaria à sua morte). Entendi que sua escolha seria essa porque o(a) Sr(a) acredita que (explicitar os valores reportados pelo paciente). Ok, então eu vou anotar aqui que, se por acaso isso ocorresse, os médicos deveriam fazer assim.*

APÊNDICE C - Formulário POLST

## Prescrição Médica para Tratamento Relacionado ao Suporte de Vida (POLST Brasil)

*Este formulário representa uma prescrição médica acerca de tratamentos de suporte de vida para o paciente nomeado abaixo. Trata-se de uma prescrição do médico que assina este documento sobre como proceder em relação ao paciente em situações clínicas que envolvam tomada de decisão sobre tratamentos de suporte de vida. Esta prescrição é fruto de um processo de discussão de preferências de tratamento e valores pessoais entre o médico e o paciente e/ou seu representante. (Mais detalhes no verso)*

***Siga esta prescrição médica até que a mesma seja modificada. Qualquer seção não preenchida implica em tratamento invasivo máximo de suporte de vida dentro daquela seção.***

| | | | |
|---|---|---|---|
| **Nome do Paciente:** | | | |
| **Endereço:** | | | **RG:** |
| **Cidade:** | **Estado:** | **Data de Nascimento (dia/mês/ano):** | |
| **CEP:** | | **Sexo:** ☐ **Masculino** ☐ **Feminino** | |

### A — Assinale apenas uma opção

**RESSUSCITAÇÃO CARDIOPULMONAR (RCP)** *(Paciente não responsivo, sem pulso e sem respiração.)*

☐ **Tentar ressuscitação / RCP**

☐ **Permitir Morte Natural / Não Tentar Ressuscitação**

*Na ausência de parada cardiorrespiratória, siga as orientações **B** e **C**.*

### B — Assinale apenas uma opção

**INTERVENÇÕES MÉDICAS** *(Se o paciente tem pulso e está respirando)*

*Medidas de conforto integram todos os níveis de intervenção médica abaixo e sempre devem ser fornecidas*

☐ **Somente Medidas de Conforto.** Fornecer tratamentos para alívio da dor e sofrimento através do uso de medicamentos por qualquer via, posicionamento no leito, mudança de decúbito, cuidado com feridas e outras medidas. Usar oxigênio, aspiração e tratamento manual para obstrução de vias aéreas (ex. posicionamento adequado da cabeça e remoção de secreções orais), conforme necessário para conforto. O paciente prefere não ser encaminhado ao hospital para tratamentos de suporte de vida. **Encaminhar ao hospital se as necessidades de conforto** não puderem ser alcançadas no local onde o paciente se encontra.
**Plano de tratamento:** Fornecer tratamento para o conforto através do alívio dos sintomas.

☐ **Tratamento Limitado.** Além dos tratamentos descritos na opção "Somente Medidas de Conforto", utilizar tratamento médico, antibióticos, hidratação IV em acesso venoso periférico ou central e monitoramento cardíaco, conforme indicado. Não intubar, não realizar intervenções avançadas de vias aéreas ou ventilação mecânica. Pode-se considerar suporte de vias aéreas não invasivo (ex., CPAP, BIPAP). Encaminhar ao hospital, se indicado. De forma geral, evitar Unidade de Terapia Intensiva (UTI).
**Plano de tratamento:** Fornecer tratamentos médicos básicos.

☐ **Tratamento Invasivo Completo.** Além dos tratamentos descritos nas opções "Somente Medidas de Conforto" e "Tratamento Limitado", realizar intubação traqueal, intervenções avançadas de vias aéreas, e ventilação mecânica conforme indicado. Encaminhar ao hospital e/ou Unidade de Terapia Intensiva se indicado.
**Plano de tratamento:** Todos os tratamentos incluindo o uso de ventilação mecânica.

**Instruções adicionais:** _____

### C — Assinale apenas uma opção

**NUTRIÇÃO POR VIA ARTIFICIAL:** *(Oferecer alimentos e líquidos por via oral se possível.)*

☐ Nutrição artificial por sonda (ex. sonda nasoenteral e gastrostomia) a longo prazo.

☐ Utilizar sonda de alimentação artificial (ex. sonda nasoenteral e gastrostomia) por período de tempo limitado.

☐ Não utilizar sonda de alimentação artificial (ex. sonda nasoenteral e gastrostomia).

**Instruções adicionais:** _____

### D — OBRIGATÓRIO

**DOCUMENTAÇÃO DA DISCUSSÃO** (OBRIGATÓRIO) Informações adicionais no verso.

A discussão que fundamentou a prescrição médica contida neste formulário foi realizada com:

☐ Paciente (Se o paciente estiver incapaz para tomar decisões, deve-se marcar a opção abaixo)

☐ Representante do paciente.

Nome do Representante: _____

Grau de parentesco/Tipo de relacionamento: _____

### E

**ASSINATURA DO PACIENTE OU REPRESENTANTE**

| | |
|---|---|
| **Assinatura: (RECOMENDADO)** | O paciente ou seu representante autorizam a inclusão das informações deste formulário em banco de dados institucional. SIM ☐ NÃO ☐ |

### F — OBRIGATÓRIO

**CERTIFICAÇÃO PELO MÉDICO (OBRIGATÓRIO)**

Assinando abaixo, eu atesto que esta prescrição médica é, ao meu melhor conhecimento, consistente com as atuais condições e preferências de tratamentos do paciente.

| | | | |
|---|---|---|---|
| **Nome do médico (Obrigatório):** | | **Telefone:** | **CRM:** |
| **Assinatura do médico (Obrigatório):** | **Carimbo:** | **Data (obrigatório):** | Uso administrativo apenas. |

**ENVIAR ESTE FORMULÁRIO COM O PACIENTE SEMPRE QUE TRANSFERIDO OU DE ALTA**

**Informações para o paciente nomeado neste formulário. NOME DO PACIENTE:**

Este formulário é preenchido **sempre de forma voluntária** e é geralmente indicado para pessoas portadoras de doenças graves ou saúde frágil. A prescrição médica aqui representada tem como objetivo traduzir seus desejos em termos de tratamentos médicos com base em seu estado de saúde atual (ou seja, suas preferências sobre tratamentos médicos caso algum problema sério de saúde ocorresse hoje à noite). Uma vez que o tratamento tenha sido iniciado e os riscos e benefícios de outros tratamentos estejam mais claros, suas preferências de tratamento podem mudar. Por isso, o seu tratamento médico e este formulário podem ser modificados a qualquer momento para refletir suas novas preferências de cuidados de saúde. No entanto, nenhum formulário jamais será capaz de abordar todas as decisões sobre tratamentos que podem ser necessárias. Por isso, um documento mais abrangente denominado Diretivas Antecipadas de Vontade é recomendado a todos os adultos capazes para tomada de decisão e permite que você documente em detalhes suas instruções para cuidados de saúde futuros e/ou nomeie um representante para falar em seu nome caso você se encontre impossibilitado de fazê-lo. Por favor, considere rever suas Diretivas Antecipadas de Vontade em conjunto com seu médico.

**Informações de Contato (opcional)**

| Representante do paciente para tomada de decisão sobre sua saúde: | Relacionamento ou grau de parentesco com paciente: | Número de telefone: | Endereço: |
|---|---|---|---|
| | | | |

**Orientações para os Profissionais de Saúde**

**Preenchendo este Formulário (POLST Brasil)**

- **O preenchimento deste formulário é voluntário.** A resolução 1995/2012* do Conselho Federal de Medicina (CFM) determina que todo médico deve levar em consideração as Diretivas Antecipadas de Vontade do paciente nas decisões sobre cuidados e tratamentos de pacientes que se encontram incapazes de se comunicar ou expressar de maneira livre e independente seus desejos. Esta resolução também determina que o médico registrará em prontuário as Diretivas Antecipadas de Vontade que lhe forem comunicadas pelo paciente. A resolução 1805/2006** do CFM determina que "é permitido ao médico limitar ou suspender procedimentos e tratamentos que prolonguem a vida do doente em fase terminal, de enfermidade grave e incurável, respeitada a vontade da pessoa ou de seu representante legal". O presente formulário tem como objetivo traduzir os valores e as preferências de cuidado dos pacientes no fim da vida em uma prescrição médica de forma a facilitar a prestação de cuidados consistentes com tais valores e preferências.

* A resolução 1995/2012 do CFM foi julgada como constitucional pela Justiça Federal conforme processo nº 1039-86.2013.4.01.3500/7100
** A resolução 1805/2006 do CFM foi julgada como constitucional pela Justiça Federal conforme processo nº 2007.34.00.014809-3.

- **Este formulário não substitui Diretivas Antecipadas de Vontade existentes.** Quando tais diretivas estiverem disponíveis, revise-as juntamente com este formulário para se certificar de que há consistência entre os dois documentos e para atualizá-los com o intuito de resolver possíveis conflitos.
- Este formulário deve ser preenchido por um médico e baseado nas preferências do paciente e indicações médicas
- Um representante para tomada de decisões pode fornecer informações para o preenchimento deste formulário e assiná-lo somente se o paciente não possuir capacidade para tanto ou se o paciente designar que a autoridade do representante como tal entre em vigor imediatamente.
- Este formulário deve ser assinado por um médico para que tenha validade. A assinatura do paciente ou de seu representante é recomendável mas não é obrigatória (ex. paciente analfabeto). Instruções verbais são aceitáveis mediante assinatura posterior pelo médico de acordo com a política institucional local.
- O uso do formulário original é fortemente recomendado. Fotocópias e faxes deste formulário assinados são válidas. Uma cópia deve ser mantida nos registros médicos do paciente em papel de cor Ultra Rosa quando possível.

**Como Utilizar este Formulário**

- Qualquer seção não preenchida deste formulário implica em tratamento invasivo completo para aquela seção.

**Seção A**

- Se for encontrado sem pulso e sem respiração, nenhum desfibrilador (incluindo desfibriladores automáticos externos) ou compressões torácicas devem ser usados em um paciente que tenha escolhido "Permitir Morte Natural / Não Tentar Ressuscitação".

**Seção B**

- Quando o conforto não pode ser alcançado no ambiente atual, o paciente, incluindo alguém cuja opção tenha sido "Somente Medidas de Conforto", deve ser encaminhando a um ambiente capaz de fornecer conforto (ex. encaminhamento ao hospital para tratamento de uma fratura de fêmur).
- Ventilação não invasiva com pressão positiva, descrita em "Tratamento Limitado", inclui pressão positiva contínua nas vias aéreas (CPAP), pressão positiva em vias aéreas a dois níveis (BiPAP), e respiração assistida por bolsa-válvula-máscara (ex. AMBU).
- Antibióticos e hidratação endovenosa geralmente não fazem parte das medidas previstas no item "Somente Medidas de Conforto".
- Tratamento de desidratação é uma medida de prolongamento da vida. Se um paciente deseja fluidos IV, indique "Tratamento Limitado" ou "Tratamento Invasivo Completo".

**Revisão do Formulário**

É recomendado que este formulário seja revisado periodicamente. A revisão é recomendada especialmente quando:

- O paciente é transferido de um ambiente ou nível de cuidados para outro; ou
- Há uma mudança substancial no estado de saúde do paciente; ou
- Se as preferências de tratamento do paciente mudam.

**Alteração e Anulação do Formulário.**

- Um paciente com capacidade de decisão pode, a qualquer momento, requerer tratamento alternativo ou anular este formulário por qualquer meio que indique sua intenção de revogá-lo. É recomendado que a revogação seja documentada traçando-se uma linha através das Seções de A a D, escrevendo a palavra **ANULADO** em letras grandes, datando e assinando sobre a linha.
- O representante para tomada de decisão pode requerer a modificação das instruções contidas nesse formulário em colaboração com o médico baseado nos desejos conhecidos do paciente ou, se desconhecidos, no melhor interesse do paciente.

**ENVIAR ESTE FORMULÁRIO COM O PACIENTE SEMPRE QUE TRANSFERIDO OU DE ALTA**

# APÊNDICE D - Questionário sobre condições clínicas, sociodemográficas, capacidade de decisão e funcionalidade

| Questionário referente pesquisa de Mestrado: Adaptação Transcultural do Instrumento POLST | | | |
|---|---|---|---|
| **1- Identificação:** | | | |
| **Nome do Paciente:** | | **RG-HC:** | |
| **Data de nascimento:** | **Nº Paciente na Pesquisa:** | **Sexo:** ☐ F ☐ M | |
| **Etnia:** ☐ Branco ☐ Negro ☐ Pardo ☐ Amarelo ☐ Indígena | | **Religião:** | |
| **Anos de Escolaridade do paciente:** _____. ☐ Alfabetizado ☐ Analfabeto funcional ☐ Analfabeto | | | |
| **A entrevista foi realizada com:** ☐ Paciente sozinho ☐ Paciente com acompanhante ☐ Representante | | | |
| **2- Dados do Representante.** Preencher somente se o entrevistado foi um representante do paciente | | | |
| **Relação com paciente:** ☐ Cônjuge/companheiro(a) ☐ Filho(a) ☐ Pai/mãe ☐ Outro:_____ | | | |
| **Sexo do representante:** ☐ F ☐ M | **Idade:** | **Religião:** | |
| **Anos de Escolaridade do representante:**_____. ☐ Alfabetizado ☐ Analfabeto funcional ☐ Analfabeto | | | |
| **3- Motivo da Internação** (conforme dados do prontuário): | | | |
| | | | |
| **4- Diagnósticos** (conforme dados do prontuário): | | | |
| 1- | 7- | | |
| 2- | 8- | | |
| 3- | 10- | | |
| 4- | 11- | | |
| 5- | 12- | | |
| 6- | 13- | | |

| **5- Avaliação da Capacidade de Decisão** | **Sim** | **Não** |
|---|---|---|
| 1). Consegue comunicar suas escolhas de tratamento médico com base nos seus valores pessoais? | | |
| 2). Compreende as informações relevantes sobre seu estado de saúde, opções de tratamento com suas vantagens e desvantagens associadas? | | |
| 3). Compreende as consequências das escolhas associadas com as diferentes opções de tratamento? | | |
| 4) Consegue esclarecer os motivos e valores que fundamentam sua decisão? | | |

| **6- Palliative Performance Status Scale (ver tabela no verso)** | **Índice (%)** | **Basal (antes internação)** | **Atual** |
|---|---|---|---|
| Vide quadro no verso | 100% | | |
| | 90% | | |
| | 80% | | |
| | 70% | | |
| | 60% | | |
| | 50% | | |
| | 40% | | |
| | 30% | | |
| | 20% | | |
| | 10% | | |
| | 0% | | |

| **7- Critérios de Inclusão:** | **Sim** | **Não** |
|---|---|---|
| • Possuir 21 anos de idade ou mais | | |
| • Ser usuário dos serviços do HC-FMB | | |
| • Uma resposta negativa de ao menos um dos médicos responsáveis pelos cuidados do paciente à seguinte pergunta: "Você ficaria surpreso se este (a) paciente vir a falecer no intervalo de um ano? " | | |
| • No momento do convite para participar no estudo ter expectativa de duração de internação de ao menos 7 dias conforme relato de um dos médicos envolvidos no cuidado do paciente. | | |
| • Concordar em participar do estudo e assinar o termo de consentimento livre e esclarecido. | | |
| **8- Critérios de Exclusão:** | **Sim** | **Não** |
| Demonstrar não possuir capacidade de decisão atendendo os 4 critérios elencados acima. OBS: Caso o paciente não possua capacidade de decisão, pode-se convidar seus familiares para participar na pesquisa. | | |

| **12- Nome do Entrevistador:** | **Data da entrevista** |
|---|---|
| | |

# APÊNDICE E – Escala de performance paliativa

| | Deambulação | Atividade e evidência da doença | Auto-cuidado | Ingesta | Nível da Consciência |
|---|---|---|---|---|---|
| **PPS 100%** | Completa | Atividade normal e trabalho; sem evidência de doença | Completo | Normal | Completa |
| **PPS 90%** | Completa | Atividade normal e trabalho; alguma evidência de doença | Completo | Normal | Completa |
| **PPS 80%** | Completa | Atividade normal com esforço; alguma evidência de doença | Completo | Normal ou reduzida | Completa |
| **PPS 70%** | Reduzida | Incapaz para o trabalho; doença significativa | Completo | Normal ou reduzida | Completa |
| **PPS 60%** | Reduzida | Incapaz para hobbies/trabalho doméstico; doença significativa | Assistência ccasional | Normal ou reduzida | Completa ou períodos de confusão |
| **PPS 50%** | Maior parte de tempo sentado ou deitado | Incapacitado para qualquer trabalho; doença extensa | Assistência considerável | Normal ou reduzida | Completa ou períodos de confusão |
| **PPS 40%** | Maior parte do tempo acamado | Incapaz para a maioria das atividades; doença extensa | Assistência quase completa | Normal ou reduzida | Completa ou sonolência +/- confusão |
| **PPS 30%** | Totalmente acamado | Incapaz para qualquer atividade; doença extensa | Dependência completa | Normal ou Reduzida | Completa ou sonolência +/- confusão |
| **PPS 20%** | Totalmente acamado | Incapaz para qualquer atividade;doença extensa | Dependência completa | Mínima a pequenos goles | Completa ou sonolência +/- confusão |
| **PPS 10%** | Totalmente acamado | Incapaz para qualquer atividade; doença extensa | Dependência completa | Cuidados com a boca | Sonolento ou coma. +/- confusão |
| **PPS 0%** | Morte | - | - | - | - |

APÊNDICE F – Artigo publicado no periódico JAMA Network Open

JAMA Network Open

Original Investigation | Geriatrics

# Evaluation of the Interrater Reliability of End-of-Life Medical Orders in the Physician Orders for Life-Sustaining Treatment Form

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## Abstract

**IMPORTANCE** Despite its spread in much of the United States and increased international interest, the Physician Orders for Life-Sustaining Treatment (POLST) paradigm still lacks supporting evidence. The interrater reliability of the POLST form to translate patients' values and preferences into medical orders for care at the end of life remains to be studied.

**OBJECTIVE** To assess the interrater reliability of the medical orders documented in POLST forms.

**DESIGN, SETTING, AND PARTICIPANTS** This cross-sectional study was conducted in a public university hospital in southeastern Brazil. Two independent researchers interviewed the same patients or decision-making surrogates (n = 64) during a single episode of hospitalization within a time frame of 1 to 7 days. Eligible participants were hospitalized adults aged 21 years or older who were expected to remain hospitalized for at least 4 days and whose attending physician responded no to the question, Would I be surprised if this patient died in the next year? Data collection occurred between November 1, 2015, and September 20, 2016, and first data analyses were performed on October 3, 2016.

**MAIN OUTCOMES AND MEASURES** Interrater reliability as measured by κ statistics.

**RESULTS** Of the 64 participants interviewed in the study, 53 (83%) were patients and 11 (17%) were surrogates. Patients' mean (SD) age was 64 (14) years, and 35 patients (55%) and 8 surrogates (73%) were women. Overall, in 5 cases (8%), disagreement in at least 1 medical order for life-sustaining treatment was found in the POLST form, changing from the first interview to the second interview. The κ statistic for cardiopulmonary resuscitation was 0.92 (95% CI, 0.80-1.00); for level of medical intervention, 0.89 (95% CI, 0.76-1.00); and for artificially administered nutrition, 0.92 (95% CI, 0.83-1.00).

**CONCLUSIONS AND RELEVANCE** The high interrater reliability of the medical orders in POLST forms appears to offer further support for this advance care planning paradigm; in addition, the finding that this interrater reliability was not 100% underscores the need to ensure that patients or their surrogates have decision-making capacity and to confirm that the content of POLST forms accurately reflects patients' current treatment preferences.

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## Key Points

**Question** What is the interrater reliability of medical treatment orders documented in the Physician Orders for Life-Sustaining Treatment form?

**Findings** In this cross-sectional study of interviews with 64 patients and decision-making surrogates in Brazil, the κ statistics for cardiopulmonary resuscitation, level of medical intervention, and artificially administered nutrition were high. However, disagreement in at least 1 order for life-sustaining treatment was found in 5 cases.

**Meaning** The findings support the Physician Orders for Life-Sustaining Treatment paradigm as a means to translate patients' values and preferences of care at the end of life into medical orders and stress the importance of frequently reviewing the content of the Physician Orders for Life-Sustaining Treatment form to ensure it reflects current preferences.

+ Supplemental content

Author affiliations and article information are listed at the end of this article.

## Introduction

The Physician Orders for Life-Sustaining Treatment (POLST) paradigm was created in Oregon in the early 1990s as a coordinated system to elicit, document, and communicate the preferences of patients regarding medical interventions at the end of life.[1,2] The POLST paradigm was developed with the ethical purpose of increasing the chances of patients' values and preferences being respected at the end of their lives by the provision of medical care that is consistent with their values. It is primarily intended for patients with limited life expectancy and translates patients' values and preferences of care into a document (the POLST form), which comprises a standardized set of medical orders concerning life-sustaining interventions. A systematic review of studies about POLST found evidence that preferences of care documented as medical orders in POLST forms are more likely to guide care at the end of life than traditional advance directives alone.[3] The "Dying in America" report by the Institute of Medicine recognized POLST as an important area of progress toward the provision of end-of-life care that is consistent with patients' values, and the report recommended the federal government to encourage US states to implement POLST programs.[4] Within the past decade, POLST has been instituted or is in the process of being implemented in 46 of the 50 states[5] and has recently raised international interest as a means to promote advance care planning and respect of patients' values at the end of life.[6]

Despite the recognition of POLST's importance, there are several gaps in the evidence about POLST.[3,7] One major underappreciated evidence gap is the absence of studies assessing the interrater reliability of the POLST form to translate patients' values into medical orders. Assessment of this psychometric property of the POLST form is important because it indicates to what extent one can trust that different clinicians, following a similar advance care planning approach, would arrive at the same set of medical orders documented in a POLST form. Hence, we designed the present study to assess the interrater reliability of the POLST form completion process to capture treatment preferences at the end of life.

## Methods

This cross-sectional study was approved by the ethics research committee of Botucatu Medical School. All participants (ie, patients or their surrogates) signed informed consent forms. Data collection occurred between November 1, 2015, and September 20, 2016, and first data analyses were performed on October 3, 2016.

This study was based on the Consensus-based Standards for the Selection of Health Measurement Instruments[8-10] and followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guideline[11] for cross-sectional studies and the Guidelines for Reporting Reliability and Agreement Studies (GRRAS) reporting guideline[12] for studies of reliability and agreement.

The study was conducted at a single public university hospital in southeastern Brazil. Two of our independent researchers (G.B.L., J.J.C.R., A.M.R., A.F.N., M.A.M., C.G.F.F., C.S.C., J.F.L.S., R.R., and E.I.O.V.) interviewed the same patients or decision-making surrogates during a single episode of hospitalization and within a time frame of 1 to 7 days. The choice of this short time frame was intended to minimize the chance of loss to follow-up and the probability that changes in the state of patient health or care could jeopardize the assessment of interrater reliability.

Patients were eligible for the study if they were aged 21 years or older, were inpatients at the study hospital, and were expected to remain hospitalized for at least 4 days and if 1 of their attending physicians answered no to the following question: Would I be surprised if this patient died in the next year?[13] If a potentially eligible patient was found during the first interview not to have decision-making capacity but to have a surrogate, the surrogate was invited to participate in the research. Decision-making capacity was determined using the following criteria as described by Appelbaum[14]: (1) ability to communicate a choice, (2) understanding of the information communicated, (3)

appreciation for the current medical condition and the likely consequences of different treatment options, and (4) ability to provide a set of reasons for the choice based on personal values. The assessment of decision-making capacity was performed during each advance care planning interview in which interviewers presented patients with a set of clinical situations, treatment options, and possible outcomes and observed how patients dealt with the information given, asked questions, expressed choices, and relayed back their understanding and the reasons for their preferences. Exclusion criteria were (1) the unavailability of the patient to participate in the second interview (eg, because of hospital discharge) and (2) the report in the beginning of the second interview that major clinical or personal events had occurred between interviews that changed the patient's perspective on end-of-life care.

During the first interview, after patients or their surrogates had signed the consent form, the interviewers collected sociodemographic data on age, sex, race/ethnicity, years of schooling, religion, main diagnosis, Charlson comorbidity index,[15] and functional status. We used the Palliative Performance Scale (score range: 0%-100%, with 0% indicating death and 100% indicating total autonomy plus lack of active illness) to rate functional status.[16] After the interview, the interviewers collected clinical data from patients' medical records, including comorbidities and the principal diagnosis that led to hospital admission.

One third-year medical student (C.S.C.), 3 fourth-year medical students (J.J.C.R., C.G.F.F., and A.F.N.), 3 interns (J.F.L.S., R.R., and A.M.R.), 1 internal medicine resident (M.A.M.), 1 psychiatrist (G.B.M.), and 1 geriatrician (E.I.O.V.) composed the team of interviewers. Interviewers were trained in the structured advance care planning conversation and in the completion of the POLST form. Training sessions were face to face and interactive, took 1 to 1½ hours each, and were provided in small groups or individually. The advance care planning conversation approach in which the interviewers were trained was based on the POLST conversation model produced by the Coalition for Compassionate Care of California.[17] The model consisted of the possibility of 3 standardized clinical events occurring in the patient's current functional state: cardiac arrest during an acute myocardial infarction, severe pneumonia with respiratory failure, and coma after a major stroke. Interviewers were trained to ask patients to confirm their understanding of the information and situations that were presented during the advance care planning conversation. Specifically, interviewers required patients to relay back their interpretation of the information and to explain the reasoning behind their care preferences and their understanding of the likely consequences of the implementation of their preferences.

Each interviewer participated in as many training sessions needed to be considered confident in conducting such a conversation within the role-play scenarios presented in each session. A specific competency checklist to assess interviewers' readiness to begin interviewing patients was not used; however, we required that both the trainer (E.I.O.V.) and the interviewer under training agreed on the interviewer's readiness. The trainer focused specific attention on how interviewers framed situations, chose words, confirmed understanding, and recognized evidence of impaired decision-making capacity. Throughout the training sessions, the trainer pointed out how subtle wording choices could unduly persuade patients in a given direction. The minimum number of training sessions was 4 and the maximum was 10.

Interviewers who performed the second interview did not have access to the content of the first interview and were specifically instructed to avoid any conversation with patients about the first interview. Likewise, participants were instructed not to share with the second interviewer any aspect of the first interview because such behavior would jeopardize the research aims.

We used a POLST form that was recently cross-culturally adapted in Brazil[6] and was mostly based on the 2014 version of the POLST form from the state of Oregon. The Brazilian POLST form has 3 sections for documenting medical orders. Section A pertains to a situation in which the patient is found unresponsive, pulseless, and not breathing and indicates orders to attempt or not to attempt cardiopulmonary resuscitation (CPR). Section B pertains to the level of medical intervention to be provided if the patient has a pulse and is breathing: comfort measures only, limited treatment, or full

treatment. Section C pertains to a situation in which the patient has difficulty with oral feeding and indicates orders to provide or not to provide, and for how long to provide, artificially administered nutrition: long-term nutrition by tube, defined trial period of artificial nutrition by tube, or no artificial nutrition by tube. Examples of POLST forms in the United States can be assessed elsewhere.[18,19] Note that the POLST form is not a questionnaire for patients to fill in which medical treatments they want. Instead, clinicians complete the POLST form according to 1 or more advance care planning conversations they have had with patients, taking into account the patients' preferences for care related to their current health condition.

### Statistical Analysis

Patients' demographic and clinical data were described through frequency tables. We described categorical data as absolute numbers and proportions and continuous data as mean and SD or median and interquartile range (IQR), as appropriate.

Statistical analyses follow the principles of classical test theory.[20] This theory was chosen for its simplicity and efficiency in terms of the sample size needs.[21] Moreover, some assumptions of the alternative paradigm, the item response theory, do not apply in the context of POLST, such as the local independence between items. To explore the factors associated with the occurrence of disagreements between interviews, we used Fisher exact test when variables were categorical or Wilcoxon rank sum test when variables were continuous.[22]

We assessed interrater reliability using Cohen κ for section A of the POLST form, in which only 2 possibilities of responses exist (ie, attempt or do not attempt CPR), and weighted κ statistic for sections B and C, in which 3 possibilities of answers were given, ranging from less invasive to more invasive treatment options.[23] We adopted linear weighting as the method for the weighted κ statistic as defined a priori in the study protocol because that strategy was associated with greater simplicity of interpretation.[24] Nevertheless, following Ben-David's[25] recommendation, we performed a sensitivity analysis through the adoption of quadratic weighting to evaluate the robustness of the analyses.

We adopted $\alpha = .05$ to indicate statistical significance. We used the R software, version 3.3.3 (R Foundation for Statistical Computing)[26] for all statistical analyses.

We calculated a minimum sample size of 62 participants using the methodology proposed by Rotondi and Donner.[27] For this calculation, we considered the following guidelines: (1) distribution of marginal proportions in section B of the POLST form of 40% patient preference for comfort measures only, 49% for limited treatment, and 11% for full treatment (we derived these proportions from Hickman et al[28]); (2) values of 0.75 as the lower limit and 0.99 as the upper limit of the 95% CI for the κ statistic; (3) estimated κ value of 90%; (4) presence of 2 interviewers; and (5) $\alpha = .05$ for statistical significance.

## Results

We included 64 participants in the study, 53 (83%) of whom were patients and 11 (17%) of whom were surrogates. Thirty-five patients (55%) and 8 surrogates (73%) were women. Ten surrogates were children of patients, and only 1 surrogate was a patient's wife. The **Figure** shows the flow diagram of participants. The mean (SD) interval of time between interviews was 2 (1.9) days.

The mean (SD) age of patients was 64 (14) years, and most patients (46 [72%]) self-identified as white and Catholic (40 [62%]). The median (IQR) Charlson comorbidity index was 3 (2-4), and the median (IQR) value for the Palliative Performance Scale was 80% (60%-90%). Further data on the clinical and sociodemographic profiles of patients are shown in **Table 1**.

Overall, differences were found in the recorded orders concerning at least 1 section of the POLST form for 5 (8%) of the 64 patients. For 1 participant, the CPR orders changed from the first interview to the second interview. Another participant had discordant orders for CPR and artificial nutrition between the 2 interviews. For 2 participants, the orders for medical interventions and

nutrition were different, and for another participant the orders for nutrition changed between the 2 interviews. **Table 2** and eTable 1 in the Supplement provide further details regarding the cases of agreement and disagreement between the 2 interviews according to each section of the POLST form.

The κ statistics assessing the interrater reliability for each section of the POLST form were high and are presented with their 95% CIs in **Table 3**. The κ statistic for CPR was 0.92 (95% CI, 0.80-1.00), for level of medical intervention was 0.89 (95% CI, 0.76-1.00), and for artificially administered nutrition was 0.92 (95% CI, 0.83-1.00).

We performed an exploratory comparison of baseline patient characteristics between cases in which at least 1 disagreement in orders between interviews was observed and cases in which complete agreement was found between interviews (eTable 2 in the Supplement). The only statistically significant association we found between patients in those groups involved religion, in which Catholic and Evangelical patients had a smaller proportion of disagreement between interviews compared with patients who were Buddhist, were Spiritist, or reported no religion.

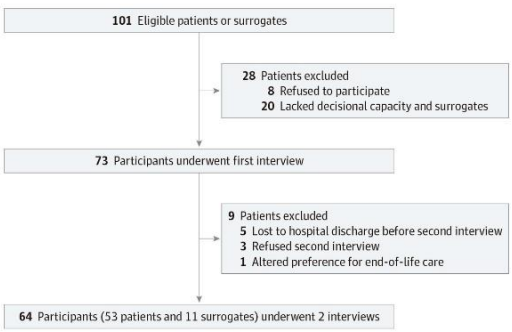
The sensitivity analysis of the weighted κ statistic that used quadratic weighting for sections B and C revealed a κ value of 0.90 (95% CI, 0.79-1.00) for section B and 0.94 (95% CI, 0.88-1.00) for section C.

## Discussion

To our knowledge, this study is the first to assess the interrater reliability of the POLST form completion process after a standardized advance care planning conversation anywhere in the world. The results point toward a high interrater reliability of the POLST paradigm to translate patients' preferences of care at the end of life into a set of medical orders for life-sustaining treatments. These results are important because they provide evidence supporting the POLST paradigm, which has spread across the United States and has raised interest internationally as a means to promote advance care planning and respect for patients' values at the end of life.[6]

However, despite the high interrater reliability we found for each section of the POLST form, we found 5 cases of disagreement between the outcomes of the 2 interviews. With regard to the discordance observed in sections B and C of the POLST form, for which there were 3 treatment options representing different degrees of life-sustaining interventions, none of the discordances involved comfort measures in one interview and full treatment in the other. Still, it is certainly disconcerting to find any cases of disagreement for medical orders for life-sustaining treatments within a very short time period. Those disagreements occurred despite our attempts to exclude patients who did not have decision-making capacity or who reported having experienced major

Figure. Flow Diagram of the Study Participants



clinical or personal events between interviews that changed their perspectives on end-of-life care. Unfortunately, the available data do not make it possible to ascertain with confidence the reasons for those disagreements. The exploratory finding that Catholic and Evangelical patients had less frequent disagreements between interviews than patients who were Buddhist, were Spiritist, or reported no religion must be regarded with great caution because of the low numbers of individuals in the latter categories and the possibility of false-positive associations when conducting multiple statistical tests.[29] The religious views of patients have been shown to affect their treatment preferences at the end of life, but we could not find studies of the association between religious beliefs and the interrater reliability of instruments used to assess those preferences in a recent systematic review about religious beliefs and major end-of-life issues.[30]

A few hypotheses may explain the cases of disagreement. First, determining decision-making capacity can require some subjective interpretation of its elements, and some patients might not have fulfilled each criterion of that capability during both interviews. A review of 15 instruments used to assess treatment-related decision-making capacity found that the interrater reliability of these instruments was imperfect, with κ values ranging from 0.44 to 0.83.[31] Second, participants might not have had a consistent opinion about care preferences and changed their minds between the interviews. We believe that the study interviews might have been the first time some participants were asked to consider issues concerning life-sustaining treatments. Third, the interviewers had not

Table 1. Clinical and Sociodemographic Profile of Patients

| Variable | No. (%) |
|---|---|
| Sex | |
| Male | 29 (45) |
| Female | 35 (55) |
| Age, mean (SD), y | 64 (14) |
| Race/ethnicity | |
| Asian | 2 (3) |
| White | 46 (72) |
| Black | 16 (25) |
| Religion | |
| Buddhism | 2 (3) |
| Catholicism | 40 (62) |
| Spiritism | 2 (3) |
| Evangelicalism | 14 (23) |
| None reported | 6 (9) |
| Years of formal education completed, median (IQR) | 4.5 (4-10.5) |
| Illiterate | 2 (3) |
| Functionally illiterate[a] | 2 (3) |
| Interview performed with | |
| Patient | 53 (83) |
| Surrogate | 11 (17) |
| Main diagnosis | |
| Cancer[b] | 38 (59) |
| Cardiovascular disease[c] | 12 (19) |
| Neurodegenerative disease[d] | 4 (6) |
| Other disorder[e] | 10 (16) |
| No. of diagnoses, median (IQR) | 3 (2.8-6) |
| Charlson comorbidity index[f] | |
| 0 | 1 (2) |
| 1 | 25 (39) |
| 2 | 21 (33) |
| 3 | 17 (27) |
| Palliative Performance Scale, median (IQR), %[g] | 80 (60-90) |

Abbreviation: IQR, interquartile range.

[a] Functional illiteracy was defined as ability to sign name but inability to read a journal or magazine article by self-report.

[b] Cancer included gastrointestinal, gynecological, breast, pulmonary, urological, and head and neck malignant neoplasms.

[c] Cardiovascular disease included chronic heart failure, coronary artery disease, and peripheral arterial disease.

[d] Neurodegenerative disease included Parkinson disease and dementia, such as Alzheimer disease and vascular dementia.

[e] Other disorder included frailty, hip fractures, liver failure, and other gastrointestinal disorders.

[f] Higher index means greater burden of comorbidities.

[g] Palliative Performance Scale score range: 0%-100%, with 0% indicating death and 100% indicating total autonomy plus lack of active illness.

been involved with the care of the patients, which could have compromised their ability to identify some subtle inconsistencies in patients' preferences. Fourth, even though the interviewers were trained in a standardized advance care planning conversation, subtle differences in the way they communicated with participants could have affected the way participants responded to the questions. Fifth, although we generally believe that humans make decisions by rationally weighing risks and rewards, we also believe that reasoning, thoughts, feelings, and decisions are affected by myriad subtle environmental and internal factors of which we are mostly unaware and that sometimes even render us unable to recognize that we have changed our minds.[32-34]

Hence, the 5 cases of disagreement in the POLST forms between the 2 interviews emphasize the importance of accurate assessment of decision-making capacity and indirectly support the concept that, ideally, advance care planning conversations should take place within an established patient-clinician relationship in which mutual trust and respect stem from previous experiences.[35] Ultimately, in real-life situations, such longitudinal relationships between patients, their surrogates, and clinicians are the most important warranty that the content of POLST forms accurately reflects patients' values and preferences of care. In addition, because miscommunication can occur even between clinicians and patients who have established relationships, the orders on a POLST form must be reviewed frequently to make sure they reflect the current preferences of the patient. In real life, patients receive a copy of their POLST form, representing another assurance that their values are reflected in those medical orders by allowing patients the opportunity to contemplate whether those orders are consistent with their current values. That patients or their surrogates can void POLST forms at any given moment represents yet another aspect of the POLST paradigm that may decrease the possibility of harm from medical orders that become inconsistent with patients' current preferences of care.

**Table 2. Summary of Medical Orders Documented in the POLST and Cases of Disagreement Between 2 Interviews**

| POLST Form Section | No. (%) | | |
|---|---|---|---|
| | First Interview | Second Interview | Disagreement |
| Section A[a] | | | 2 (3) |
| Cardiopulmonary resuscitation | 48 (75)[b] | 48 (75)[b] | |
| Allow natural death | 16 (25)[b] | 16 (25)[b] | |
| Section B[c] | | | 2 (3)[b] |
| Comfort measures only | 0 | 1 (2) | |
| Limited treatment | 10 (16) | 10 (16) | |
| Full treatment | 54 (84) | 53 (83) | |
| Section C[d] | | | 4 (6) |
| Long-term nutrition by tube | 33 (52) | 30 (47) | |
| Defined trial period of artificial nutrition | 23 (37) | 25 (31) | |
| No artificial nutrition by tube | 8 (12) | 9 (14) | |

Abbreviation: POLST, Physician Orders for Life-Sustaining Treatment.

[a] Concerns situations in which patients are found unresponsive, pulseless, and not breathing, and the decisions involve performing cardiopulmonary resuscitation or allowing natural death.

[b] The proportions and absolute numbers are equal despite the presence of 2 cases of disagreement in medical orders between the 2 interviews because the same number of individuals had their preferences of care recorded in the opposite direction between interviews.

[c] Concerns any situation in which patients have a pulse and are breathing, and the decisions involve providing medical interventions in general.

[d] Concerns situations in which patients have difficulty with oral feeding, and the decisions involve providing enteral nutrition or not.

**Table 3. Raw Interrater Agreement and κ Statistics for Each Section of the POLST Form Between the 2 Interviews of 64 Patients**

| POLST Form Section | Raw Interrater Agreement, % | κ Value (95% CI) | *P* Value |
|---|---|---|---|
| Section A: cardiopulmonary resuscitation | 96.9 | 0.92 (0.80-1.00) | <.001 |
| Section B: medical intervention | 96.9 | 0.89 (0.76-1.00) | <.001 |
| Section C: artificially administered nutrition | 93.8 | 0.92 (0.83-1.00) | <.001 |

Abbreviation: POLST, Physician Orders for Life-Sustaining Treatment.

Few studies have assessed the interrater reliability of instruments that document advance care planning conversations. A Malaysian study evaluated the intrarater test-retest reliability of a locally developed questionnaire for assessing individuals' attitudes and awareness about advance care planning but not patients' preferences of care at the end of life.[36] The κ statistic for the items of that questionnaire ranged from 0.74 to 0.95. An Australian study evaluated the interrater reliability of an advance care planning template documenting the care preferences and advance care plans of older adults in residential care facilities.[37] In the Australian study, 2 independent researchers interviewed 30 older adults within an unspecified period. The κ statistics ranged from 0.73 to 0.79, but no information was provided on the substance of disagreements in specific items of the advance care planning template that was used.

The study has some relevant implications for policy and practice. Although the high interrater reliability that we found offers support for the POLST paradigm, it was not 100% or perfect, highlighting the need to confirm the medical orders on a POLST form on subsequent patient interactions to make sure the orders accurately reflect the patients' current wishes. Future studies should assess other populations, conduct interviews with somewhat longer intervals of time, and compare preferences of care documented through POLST with different advance care planning strategies. Interrater reliability studies of other advance care planning documents in use are also much needed.

### Limitations

This study has a number of limitations. First, the interval of time between the first and second interviews was short, which may have been associated with some degree of recall bias. Nevertheless, the optimum time interval between interviews for the assessment of interrater reliability depends on the population under study and the construct being measured. The ideal interval of time should not be so long that the construct under study might change but not so short that a recall bias is incurred. Because the population under study was composed of hospitalized patients with serious illnesses, long intervals of time would have been associated with the risk of patients undergoing clinical changes that could affect the construct being measured or of losing the patient from the study because of hospital discharge. Second, we studied a population of inpatients in a university hospital in a middle-income country, which does not reflect other contexts in which POLST has been used. Most studies of POLST were conducted in long-term care facilities in the United States.[3] On the other hand, although the results may not be generalizable to other populations, they do contribute to the expansion of knowledge about POLST in previously understudied populations. Third, the interviewers were not assessed with a competency checklist to ensure they were adequately prepared to conduct advance care planning conversations. Fourth, despite the high level of interrater reliability that we identified, we cannot completely rule out the possibility that the content of POLST forms was not consistent with patients' actual values and preferences of care. An assessment of decision quality or the factors in specific treatment preferences was beyond the scope of this study.

## Conclusions

This study appears to provide evidence of high interrater reliability of the POLST completion process, thereby offering further support for this innovative advance care planning paradigm. In addition, the finding that this interrater reliability was not 100% underscores the need to ensure that patients or their surrogates have the decision-making capacity to participate in advance care planning and that a process is in place to confirm that the recorded POLST orders accurately reflect patients' current treatment preferences.

**ARTICLE INFORMATION**

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**Author Contributions:** Dr Vidal had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

*Concept and design:* Fukushima, Vidal.

*Acquisition, analysis, or interpretation of data:* All authors.

*Drafting of the manuscript:* Lovadini.

*Critical revision of the manuscript for important intellectual content:* All authors.

*Statistical analysis:* Lovadini, Vidal.

*Obtained funding:* Vidal.

*Administrative, technical, or material support:* Fukushima, Jacinto, Harrison Dening, Bassett, Moss, Steinberg, Vidal.

*Supervision:* Vidal.

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**SUPPLEMENT.**

**eTable 1.** Comparison of Medical Orders Documented in Physician Orders for Life-Sustaining Treatment (POLST) Forms From the 2 Interviews in Absolute Numbers per Individual Participants (N = 64)

**eTable 2.** A Comparison of Cases When There Was at Least One Disagreement Between Interviews and Cases When There Was Complete Agreement Between Interviews (N = 64)

# *Anexos*

# ANEXO A – Parecer consubstanciado do CEP

FACULDADE DE MEDICINA DE BOTUCATU -UNESP

## PARECER CONSUBSTANCIADO DO CEP

**DADOS DO PROJETO DE PESQUISA**

**Título da Pesquisa:** Adaptação transcultural do questionário POLST: Physician Orders for Life-Sustaining Treatment

**Pesquisador:** Edison Iglesias de Oliveira Vidal

**Área Temática:**

**Versão:** 1

**CAAE:** 42849014.3.0000.5411

**Instituição Proponente:** Departamento de Clínica Médica

**Patrocinador Principal:** Financiamento Próprio

**DADOS DO PARECER**

**Número do Parecer:** 1.012.799

**Data da Relatoria:** 06/04/2015

**Apresentação do Projeto:**

As decisões sobre continuidade de intervenções terapêuticas em pacientes graves suscitaram diversas polêmicas nas últimas décadas. Tornou-se evidente a necessidade de validar instrumentos que pudessem documentar as preferências dos pacientes quanto aos tratamentos que prolongam a vida. O questionário POLST (Physician Orders for Life Sustaining Treatment) foi desenvolvido na década de 1990 no Oregon (Estados Unidos) e teve seu uso rapidamente difundido naquele país. Embora não haja relatos sobre aplicação em outros países, é evidentemente pertinente a discussão sobre os limites do suporte de vida em todas as localidades - em especial nos países "em desenvolvimento". Além disso, questionário POLST já foi traduzido para o espanhol e o japonês. O pesquisador propõe a adaptação transcultural do questionário para uso no Brasil. Para tanto, planeja seguir as etapas usuais desse processo, incluindo: (a) discussão com experts sobre pertinência dos itens do questionário (equivalência conceitual); (b) cotejamento de duas traduções simultâneas independentes e de versão consensual realizada por observador independente, com aplicação das três versões a grupos de médicos e pacientes (equivalência semântica); (c) comparação entre aspectos da aplicação do questionário a populações-alvo (equivalência operacional); (d) avaliação de confiabilidade (concordância inter-observadores), reprodutibilidade (concordância na aplicação ao mesmo sujeito em diferentes tempos), poder

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discriminatório e consistência interna (equivalência de mensuração). A amostra total estimada é de 120 sujeitos, entre médicos e pacientes.

**Objetivo da Pesquisa:**

O objetivo do estudo é adaptar o questionário POLST para aplicação no Brasil. Um objetivo secundário é a análise das opções da população do estudo quanto a tratamentos prolongadores de vida.

**Avaliação dos Riscos e Benefícios:**

O estudo tem potencial benefício direto (por permitir aos sujeitos envolvidos melhor elaboração do tema do fim da vida e dos tratamentos agressivos para prolongá-la) e indiretos (ao contribuir para a discussão ética sobre a ortotanásia). Os riscos são pequenos, talvez associados a desconforto de sujeitos ao serem confrontados com o tema.

**Comentários e Considerações sobre a Pesquisa:**

TRATA-SE DE UM ESTUDO JÁ APROVADO POR ESTE CEP EM 03/09/2012 (Protocolo CEP 4320/2012) QUE ESTÁ SENDO TRANSFERIDO PARA PLATAFORMA BRASIL. POR ESSA RAZÃO OS PRAZOS DE CRONOGRAMA SÃO RETROSPECTIVOS. PORÉM ENTENDO QUE AINDA ESTÁ EM FASE DE ANÁLISE E ELABORAÇÃO DOS RESULTADOS.

**Considerações sobre os Termos de apresentação obrigatória:**

Apresentam-se os termos pertinentes. Os TCLE são redigidos adequadamente e em linguagem direcionada a cada grupo do estudo (pacientes e médicos).

**Recomendações:**

**Conclusões ou Pendências e Lista de Inadequações:**

RECOMENDO APROVAÇÃO SEM NECESSIDADE DE ENVIO À CONEP

**Situação do Parecer:**

Aprovado

**Necessita Apreciação da CONEP:**

Não

**Considerações Finais a critério do CEP:**

TRATA-SE DE UM ESTUDO JÁ APROVADO POR ESTE CEP EM 03/09/2012 (Protocolo CEP 4320/2012) QUE ESTÁ SENDO TRANSFERIDO PARA PLATAFORMA BRASIL, DESTA FORMA O CEP EM REUNIÃO DE 06 DE ABRIL DE 2.015 APROVOU O REFERIDO ESTUDO COMO "PROJETO ANTERIOR A PLATAFORMA BRASIL".

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O CEP SOLICITA AOS PESQUISADORES QUE AO FINAL DA EXECUÇÃO DESTE ESTUDO, SEJA ENCAMINHADO NO SISTEMA PLATAFORMA BRASIL, O RELATÓRIO FINAL DE ATIVIDADES NA FORMA DE "NOTIFICAÇÃO"

BOTUCATU, 07 de Abril de 2015

**Assinado por:**
**SILVANA ANDREA MOLINA LIMA**
**(Coordenador)**

# ANEXO B - Carta de aceite do manuscrito pela revista JAMDA

De: **JAMDA** em@editorialmanager.com
Assunto: Your Submission JAMDA-D-20-01129R1
Data: 10 de outubro de 2020 10:50
Para: Edison I. O. Vidal eiovidal.fmb@gmail.com

Manuscript Reference Number: JAMDA-D-20-01129R1
Title: To what extent do Physician Orders for Life-Sustaining Treatment (POLST) reflect patients' preferences for care at the end of life?
Journal: JAMDA

Dear Dr. Vidal:

Your manuscript entitled "To what extent do Physician Orders for Life-Sustaining Treatment (POLST) reflect patients' preferences for care at the end of life?" has been favorably reviewed, and we are pleased to accept it for publication in the next available issue of JAMDA.

We will forward your manuscript to the Elsevier Production team for preparation. You will be contacted within a few weeks to review page proofs of your article.

PLEASE NOTE: When you receive your page proofs, it is important that you ensure all errors are corrected before returning them to Elsevier. The corresponding author is responsible for correcting errors before the article goes to press.

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We appreciate and value your contribution to JAMDA, and we recognize your expertise in post-acute and long-term care. In that regard, JAMDA authors are often invited to participate in the peer review process, and based on your expertise, you may be called upon to serve as a reviewer. We look forward to your continued participation in our journal, and hope you will consider JAMDA for your future submissions.

With kind regards,

Paul R Katz, MD, CMD
Senior Associate Editor, JAMDA

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