Supplementary Online Content

Auriemma CL, Nguyen CA, Bronheim R, Kent S, Nadiger S, Pardo D, Halpern SD. Stability of end-of-life preferences: a systematic review of the evidence. *JAMA Intern Med*. Published online May 26, 2014. doi:10.1001/jamainternmed.2014.1183

This supplementary material has been provided by the authors to give readers additional information about their work.

eFigure 1. PRISMA Checklist (Part 1)

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	3
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	4
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	4
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	4
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	5
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	5
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	appendix
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	5
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	5
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	5
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	n/a
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	6
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	n/a

eFigure 2. PRISMA Checklist (Part 2)

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	n/a
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	6
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	Figure 1
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Table 1
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	n/a
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	Figure 2
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	n/a
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	n/a
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	n/a
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	7-11
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	13
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	11-14
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	15

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For more information, visit: www.prisma-statement.org.

eTable 1. Complete online search strategy

Embase (193):	('terminal care'/exp OR 'end-of-life' OR 'terminally ill patient'/exp OR 'living will'/exp OR 'advance directive'/syn OR 'advance directives'/syn OR 'life-sustaining treatment'/exp OR 'life sustaining') AND ('attitude to change'/exp OR change OR stability OR stable OR inconsist*) AND ('attitude to death'/exp OR 'patient preference'/exp OR 'decision making'/exp OR choice* OR chos*) AND ([humans]/lim AND [english]/lim)
PUBMED (860):	change* OR stability OR stable OR inconsist* AND (("Terminally Ill"[Mesh]) OR "Terminal Care"[Mesh] OR "terminal illness" OR "end of life" OR end-of-life OR "life sustaining") AND ((("Attitude to Death"[Mesh]) OR "Patient Preference"[Mesh] OR prefer*) OR "Choice Behavior"[Mesh] OR "Decision Making"[Mesh] OR decid*)

eTable 2. Studies not included in quantitative analysis due to insufficient data

Authors	Year	Country	Patient Cohort	Population Studied	Sample Size	Assessments, No.	Time between assessments	Preference(s) Queried	Method of Data Collection	Main Result
Brunner-La Rocca et al	2012	Switzer-land	Yes	Outpatients with CHF	555	2	6-12 mo	CPR	IPQ	Most subjects preferred longevity over quality of life and half wished for resuscitation with CPR if neccessary
Martin and Roverto	2006	United States	No	older community-dwelling adults	21	2	7 y	AB, AN, CPR, CX, D, MV, S	IPQ, TQ	No significant change in health care decisions was found for life-sustaining treatments during the 7-y period in study participants.
Resnick and Andrews	2002	United States	No	older adults living in continuing care retirement community	135	2	12 mo	AB, AN, B, CPR, D, MV, P, S	IPQ	Participants were willing to receive 5.6 EOL treatments at baseline and 5.5 EOL treatments at follow-up.
Nahm and Resnick	2001	United States	No	older adults living in continuing care retirement community	140	2	12 mo	AN, B, CPR, MV, P	IPQ	There was a statistically significant difference between the 2 years with regard to ELTP for CPR, receiving blood, and being placed on a respirator. There was a slight increase in the percentage of individuals who wanted CPR and blood transfusions and a slight decrease in the percentage of those who wanted to be put on a respirator.
Levenson et al	2000	United States	Yes	elderly adults hospitalized for acute exacerbation of CHF	447	4	1 wk to 3 mo	AN, CPR, MV, NH	CR, IPQ	There was an increase in the total proportion wanting DNR, and comfort care as death approached, but there

										were no data on individuals' preference changes.
Albert et al	1999	United States	Yes	outpatients with ALS	121	3	4 mo	AN, BiPAP, MV, tracheostomy	CR, IPQ	Patients with ALS were able to express their preferences for life-extending or ameliorative technologies and made choices consistent with these preferences.
Berger and Majerovitz	1998	United States	No	nursing home residents	33	2 to 3	3 mo	AN, CPR, MV, S	IPQ	There were few significant changes in treatment preferences over time, but when changes were evident, they were toward a more definite rejection of treatment.
Patrick et al	1997	United States	Yes	younger and older well adults; persons with chronic conditions, terminal cancer, or AIDS; stroke survivors; and nursing home residents.	341	4	6-12 mo	AB, AN, D, CPR, MV, S	IPQ, TQ	Patients' treatment preferences were stable; when they were shown their discordant preferences, they had a coherent explanation or changed their health state rating or treatment preference to make the 2 concordant.
Hooper et al	1996	Australia	Yes	inpatients admitted for treatment of depression	22	2	2 mo	AN, B, CPR, D, ICU, MV	IPQ	There were significant increases in the number of interventions desired overall among the patients who recovered from depression and those whose GDS scores improved.

eTable 2. Studies not included in quantitative analysis due to insufficient data (continued)

Authors	Year	Country	Patient Cohort	Population Studied	Sample Size	Assessments, No.	Time between Assessments	Preference(s) Queried	Method of Data Collection	Main Result
Walker et al	1995	United States	No	retired elderly persons	102	2	2 wk	CPR	IPQ, TQ	After receiving CPR information, patients with living wills desired less CPR in the scenarios of current state, severe illness, and terminal illness after receiving CPR information. Patients without living wills desired less CPR in the scenarios of current state, severe illness, and cognitive impairment. After responses between the 2 groups were compared, significant differences were no longer seen.
Potter et al.	1994	Scotland	Yes	older adults admitted for acute medical illness	8	2	No time specified (following "recovery")	CPR	IPQ	Patients who initially did not wish CPR mostly scored high on the geriatric depression scale, but after recovery, 38% changed their minds and wished CPR if required.
Fogel and Mor	1993	United States	Yes	outpatients with AIDS	431	2	11 mo	MV, NH	IPQ	Patients who were initially depressed and found nursing home care intolerable were significantly more likely to later accept the treatment if their depression was no longer present (45.7% vs. 28.4%).
Schneiderman	1992	United	Yes	outpatients	63	3	6 mo	AN, CPR, H,	IPQ	There is substantial

et al		States		with "life-threatening disease" and 5-year life expectancy of 50% or less				MV		stability in preferences for CPR, mechanical ventilation, artificial nutrition and hydration, and hospitalization and treatment for pneumonia.
Sample size refers to the number of individuals for whom preferences were assessed at 2 or more time points. Time between assessments is approximated based on available data. AB = antibiotics, AN = artificial nutrition and/or hydration, CPR = cardiopulmonary resuscitation, CX = chemotherapy, D = dialysis, MV = mechanical ventilation, NH = nursing home, P = procedure, S = surgery. IPQ = in-person questionnaire, MQ = mailed questionnaire, TQ = telephone questionnaire										

eTable 3. Studies not included in quantitative analysis due to focus on nonmedical treatment preferences

Author	Year	Country	Patient Cohort	Population Studied	Sample Size	Assessments, No.	Time between Assessments	Preference(s) Queried	Method of Data Collection	Main Result
Buiting et al	2012	Netherlands	No	community-dwelling older adults	1596	2 to 3	3 y	euthanasia, end-of-life pill	IPQ	There was an increase in the proportion of older people who reported that they could imagine desiring euthanasia or end-of-life pill.
Pardon et al ✢	2012/ 2010	Belgium	Yes	patients with advanced lung cancer	97	3	2-4 mo	decision-making preferences	IPQ	Most patients wanted family involvement in decision-making, but half changed their minds over time.
Breitbart et al.	2010	United States	Yes	Inpatients with advanced AIDS	250	2 to 3	1 mo	desire for hastened death	IPQ	Successful treatment for depression substantially decreased desire for hastened death in patients with advanced AIDS.
Pruchno et al	2008	United States	Yes	outpatients with ALS	27	2	6 mo	decision-making preferences	IPQ	The stability of treatment preferences varied, but the strongest predictor of treatment preferences at follow-up was initial preference.
Stevenson et al	2008	United States	Yes	patients hospitalized for advanced heart failure	287	4	1-3 mo	time trade-off	IPQ	Preferences remained in favor of survival for many patients despite advanced HF symptoms, but increased further after hospitalization.
Sulmasy et al	2007	United States	Yes	outpatients with cancer, ALS, or HF	85	3	3 mo	decision-making preferences	IPQ	Over half of patients opted for the same degree of decision control at 3 mo as at baseline, with most opting for shared decision-making.
Fried et	2007 /	United States	Yes	outpatients	189	4	4 mo	high-burden and	IPQ	35% of patients had an

al ✦	2007 / 2006			with severe COPD, CHF, or cancer				low-burden treatment		inconsistent preference trajectory when asked their willingness to undergo high-burden therapy to avoid death, increasing to 48% and 49% when asked their willingness to risk physical or cognitive disability in order to avoid death.
Schamp and Tenkku	2006	United States	Yes	elderly, frail, medically complex outpatients	160	2	12 mo	"AD pathway"	CR	The Pathways Tool was associated with increased completion of present directives (PDs) and advance directives (ADs), preferences toward less invasive levels of care at life's end, increased compliance with participants' wishes and deaths at home, decreased DNR wishes in PDs, and increased DNR wishes in ADs.
Voogt et al	2005	Netherlands	Yes	outpatients with incurable cancer	122	3	6 mo	treatment aimed at quality or length of life	IPQ, MQ	There were no changes in attitudes toward treatment 6 or 12 months after inclusion, except for patients with a history of cancer of less than 6 months at inclusion.
Pacheco et al	2003	United States	Yes	patients with noncurable malignancy	24	2 to 3	3 or 6 mo	euthanasia, PAS	IPQ	Patients became less supportive of legalizing PAS and E from the initial to last attitude measurement.
Blank et al	2001	United States	Yes	older patients hospitalized for depression	124	2	6 mo	euthanasia, PAS	IPQ, TQ	Patients depressed in the hospital and interested in PAS for the outcome of their current, non-terminal condition were significantly more likely to express unstable opinions, with most rejecting it 6 mo later.

eTable 3. Studies not included in quantitative analysis due to focus on nonmedical treatment preferences (continued)

Author	Year	Country	Patient Cohort	Population Studied	Sample Size	Assessments, No.	Time between Assessments	Preference(s) Queried	Method of Data Collection	Main Result
Lockhart et al	2001	United States	No	community-dwelling older adults	50	2	10.7 mo	desire to live or die	IPQ	88% of patients had stable preferences in the most severe condition of coma; 90% in the least severe condition of death; and an average of 69% in the 5 conditions representing more moderate disability.
Emanuel et al	2000	United States	Yes	outpatients with severe COPD, CHF, or cancer	650	2	4.5 mo	euthanasia, PAS	IPQ	Half of patients changed their preferences over a few months, with depressed patients being more likely to change their preferences for euthanasia and PAS.
Chochinov et al	1999	Canada	Yes	patients admitted to inpatient palliative care unit with terminal malignancy	168		twice a day	will to live	IPQ	The will to live is highly unstable among terminally-ill cancer patients.
Sullivan et al.	1998	Nether-lands	Yes	outpatient participants in large cohort study who reported several physical disabilities	575	2	12 mo	desire for hastened death	IPQ	Fears of death and dying were most strongly related to participants' mental health, but their preferences for hastened death were stable.
Tsevat et al	1998	United States	Yes	hospitalized patients 80 y or older	176	2	12 mo	time trade-off	IPQ	A year after hospitalization, the time patients would give up in their current state of health in

										exchange for excellent health had declined by 2 wks, on average.
Chochinov et al	1995	Canada	Yes	patients admitted to inpatient palliative care unit with terminal malignancy	6	2	0.5 mo	desire for death	IPQ	Patients' desire for death was closely associated with clinical depression, and decreased over time.
Tsevat et al	1995	United States	Yes	outpatients with 6-mo mortality rate of about 50%	855	2	2-4 mo	time trade-off	IPQ	Patients' health values varied widely, but were generally higher than their surrogates believed.

Sample size refers to the number of individuals for whom preferences were assessed at 2 or more time points. Time between assessments is approximated based on available data..
IPQ = in-person questionnaire, MQ = mailed questionnaire, TQ = telephone questionnaire
✦ Identifies 2 articles that were considered as 1 study

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