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Respecting Choices and Related Models of Advance Care Planning: A Systematic Review of Published Evidence

Meredith A. MacKenzie, PhD, RN, CRNP, CNE[1], Esther Smith-Howell, PhD, RN[2], Patricia A. Bomba, MD, FACP[3], and Salimah H. Meghani, PhD, MBE, RN, FAAN[2]

Abstract

All individuals should receive care consistent with their expressed preferences during serious and chronic illnesses. Respecting Choices (RC) is a well-known model of advance care planning intended to assist individuals consider, choose, and communicate these preferences to health-care providers. In this systematic review, we evaluated the published literature on the outcomes of the RC and derivative models utilizing criteria developed by the Cochrane Collaborative. Eighteen articles from 16 studies were included, of which 9 were randomized controlled trials, 6 were observational, and 1 was a pre–posttest study. Only 2 specifically included a minority population (African American). Fourteen were conducted in the United States, primarily in the Wisconsin/Minnesota region (n = 8). Seven studies examined the RC model, whereas 9 examined derivative models. There was significant heterogeneity of outcomes examined. We found that there is a low level of evidence that RC and derivative models increase the incidence and prevalence of Advance Directive and Physician Orders for Life-Sustaining Treatment completion. There is a high level of evidence that RC and derivative models increase patient–surrogate congruence in Caucasian populations. The evidence is mixed, inconclusive, and too poor in quality to determine whether RC and derivative models change the consistency of treatment with wishes and overall health-care utilization in the end of life. We urge further studies be conducted, particularly with minority populations and focused on the outcomes of preference-congruent treatment and health-care utilization.

Keywords

advance care planning, advance directives, decision-making, ethics, models of care, systematic review

Introduction

The goal of advance care planning (ACP) is to ensure that individuals receive care consistent with their expressed preferences during serious and chronic illnesses.[1] Unfortunately, communication about preferences frequently either does not occur or occurs very late in the course of an individual's illness trajectory, sometimes mere days or weeks before death.[2,3] This leaves many individuals and families struggling to make decisions in a pressured, emotional, and time-sensitive situation and leads to preference-discordant care.[4,5]

Thus, a key recommendation of the 2014 Institute of Medicine (National Academy of Medicine, Engineering and Science) report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, was to normalize end-of-life (EOL) conversations through engagement of persons and families in care planning over time.[6] The report also indicated a clear distinction between an advance directive (AD)—a static document for expressing EOL wishes—and ACP—a process of care planning over time[6] (Table 1). Similarly, a recent Delphi survey of palliative care experts defined ACP as a process of care "that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care."[1(p821)] Advance care planning acknowledges that individuals' preferences often evolve as their health status worsens and the conversation around preferences should also evolve.[7-9]

Respecting Choices (RC) is one well-known model intended to normalize EOL communication.[6] The RC model started in La Crosse, Wisconsin in 1991 as a community-wide initiative of integrating ACP.[10] The key features of the program include a stepped approach to ACP (First Steps, Next Steps, and Last Steps) and in-depth counseling by trained nonphysician

[1] College of Nursing, Villanova University, Villanova, PA, USA
[2] School of Nursing, University of Pennsylvania, Philadelphia, PA, USA
[3] Geriatrics, Excellus BlueCross BlueShield and MedAmerica Insurance Company, Rochester, NY, USA

Corresponding Author:
Meredith A. MacKenzie, PhD, RN, CRNP, CNE, Villanova University, 800 E. Lancaster Avenue, Driscoll Hall Rm. 314, Villanova, PA 19085, USA.
Email: meredith.mackenzie@villanova.edu

Table 1. Advance Care Planning Terms.

Advance care planning[a]	
"The whole process of discussion of end-of-life care, clarification of related values and goals, and embodiment of preferences through written documents and medical orders. This process can start at any time and be revisited periodically, but it becomes more focused as health status changes. Ideally, these conversations (1) occur with a person's health-care agent and primary clinician, along with other members of the clinical team; (2) are recorded and updated as needed; and (3) allow for flexible decision-making in the context of the patient's current medical situation."	
Terms related to advance care planning[a]	
Advance directives	"Refers to several types of patient-initiated documents, especially living wills and documents that name a health-care agent." "Living will—a written (or video) statement about the kinds of medical care a person does or does not want under certain specific conditions (often "terminal illness") if no longer able to express those wishes." Durable power of attorney for health care—identifies the person (the health-care agent) who should make medical decisions in case of the patient's incapacity.
Medical orders	"Are created with and signed by a health professional, usually a physician (in some states, a nurse practitioner or physician assistant), for someone who is seriously ill. Because they are actual doctor's orders, other health professionals, including emergency personnel, are required to follow them." "Physician Orders for Life-Sustaining Treatment (POLST)[b]—physician orders covering a range of topics likely to emerge in care of a patient near the end of life. The orders cross care settings and are honored in the community in an emergency." "The names of similar forms in different states vary."

Abbreviations: IOM, Institute of Medicine.
[a]Definitions from IOM.[6]
[b]The names of similar forms in different states vary.

facilitators. The program features include treating ACP as an ongoing process, shifting focus from completion of the documents and toward facilitating discussion about values and goals, shifting the locus of ACP away from hospitals and physicians into the community and family, training of nonphysician community volunteers, refocusing discussion of preferences in terms of personal relationships and away from individual autonomy, and ensuring that completed ADs are available in patients' charts.[11] Later, the model was expanded to include the Physician's Order for Life-Sustaining Treatment (POLST) paradigm.[12] Physician's Order for Life-Sustaining Treatment is a communication process that emphasizes shared decision-making based on the patient's current health status, prognosis, and goals and results in the completion of a set of medical orders. Physician's Order for Life-Sustaining Treatment is not an AD based on future care preferences.[13]

The RC program showed very promising early results. Of 540 decedents in the Gundersen Lutheran Medical Center 2 years postimplementation, 85% had a written AD, which was found in the patients' medical record in 95% of cases.[14] Over the years, several studies on RC and its adaptations have been reported in the literature and there have been efforts to scale the model to the national and international levels,[15] including partnering with the Coalition to Transform Advanced Care (C-TAC) as part of its Service Affiliate C-TAC Innovations.[16] However, despite the promise of widespread integration, the published evidence for the RC model has not been adequately synthesized to inform its broad adoption across care settings.

The purpose of this systematic review (1991-2017) is to synthesize the published evidence on RC model and related models adapting RC for types of ACP outcomes studied, population and settings of implementation, and effectiveness of the model in improving various ACP and EOL outcomes. We also evaluate the published findings for methodological rigor and study characteristics.

Respecting Choices Model Description

The RC model is a copyrighted systematic program licensed by Gundersen Health System designed to promote ACP. The model utilizes First Steps, Next Steps, and Last Steps components corresponding to different phases of life and illness trajectory (wellness, illness diagnosis, and advanced serious illness). To be certified as an RC trainer or facilitator, a 20-hour training is required.[17] Facilitators can be trained only on First Steps, Next Steps, or Last Steps for the RC model and are trained only in Next Steps and Last Steps for disease-specific ACP (DS-ACP) and patient-centered ACP (PC-ACP) as these models are intended to be used in people who already have a serious life-limiting illness.

Methods

Search Methods and Databases

The systematic review methods were adapted from the process developed by the Cochrane Collaboration.[18-21] The search was conducted between November 2016 and April 2017 using PubMed, Cumulative Index of Nursing and Allied Health Literature (CINAHL), and Google Scholar electronic databases. PubMed is one of the leading biomedical databases, while CINAHL has a focus more inclusive of nursing and psychology. To provide the broadest results, Google Scholar was also utilized. The keywords included "respecting choices," "honoring choices," "disease-specific advance care planning," "patient-

centered advance care planning," combined with "advance care planning," "end of life," and "goals of care." The reference lists of articles were reviewed to identify any additional articles.

Criteria for Inclusion of Studies

Published, peer-reviewed, empirical studies testing the RC model and close derivatives including Honoring Choices, DS-ACP, and PC-ACP were included in the review. Honoring Choices and DS-ACP are known variants of RC. Disease-specific ACP was developed by the RC program to tailor the RC model to patients with specific life-limiting diseases, including heart failure and end-stage renal disease.[22] The PC-ACP is also tailored toward patients with life-limiting diseases and combines the RC model with the theories of interactive decision-making and the representational approach to patient education.[23] Only articles published in English language were included. We excluded review articles, those that did not test a patient-centered outcome (eg, discussion of implementation without examination of results or evaluation of facilitator comfort), or those that only evaluated the feasibility and acceptability of the intervention. We excluded articles that presented a protocol only, but when a protocol was found, we followed up to see whether the final study had been published. We also excluded book chapters, unpublished dissertations, and conference proceedings.

Study Quality and Assessment of Bias

The study quality was evaluated using Grading of Recommendations Assessment, Development and Evaluation (GRADE) criteria, and the tool for assessing risk of bias developed by the Cochrane Collaborative was utilized for assessing the risk of bias in each study.[18-21,24]

Results

Description of Studies

The search of the electronic databases (conducted November 2016 to April 2017) initially yielded 745 unique articles. The study selection and screening process are shown in Figure 1. Eighteen articles from 16 studies were included in the final review.

Study Characteristics

Of the included studies, 9 were randomized controlled trials (RCTs[23,25-35]; 5 of which were pilot studies or smaller studies with less than 32 participants or dyads[23,26,31,32,34,35]), 6 were observational,[22,13,17,36-38] and 1 was a pretest–posttest study design.[39] Fourteen were conducted in the United States, primarily in Wisconsin and/or Minnesota (n = 8) and 4 even more specifically in La Crosse, Wisconsin.[13,23,27,28,35] Two were conducted internationally (Australia and Germany).[17,25]

Participant Characteristics

Participant characteristics such as race and ethnicity were not consistently reported; 2 studies were predominantly or exclusively with blacks/Africa -Americans,[26,34] while 5 were predominantly or exclusively with whites/Caucasians.[23,27,28,35,36] Two of the studies were conducted with adolescent samples,[29-32] while the majority (n = 14) was performed with adults or older adults. Eight were focused on a particular diagnosis group such as cardiovascular or renal disease (n = 5),[22,23,27,28,34,35,40] HIV (n = 1),[30] or cancer (n = 2),[31,32,38] whereas 6 studies did not limit by specific diagnosis (Table 2).

Interventions

Seven completed studies examined the RC model,[13,17,25,33,36-38] whereas 9 examined RC adaptations, which included RC combined with 5 wishes or motivational interviewing (n = 2),[30-32] PC-ACP (n = 4),[23,27,28,34,35] and DS-ACP (n = 3).[22,29-32] None of the eligible studies examined the Honoring Choices model.

The use of First Steps, Next Steps, and Last Steps. Only 1 study included healthy adults and appropriately utilized the First Steps component.[26] A second study involved adults with cancer, who would be appropriate for Next Steps, but the interventionists were trained with First Steps.[38] One study included nursing home residents with a less than 1 year life expectancy and utilized the Last Steps component.[39] The other studies enrolled patients with life-limiting illnesses and used either Next Steps exclusively (n = 10 studies)[22,23,25,27,28,33-35,36,37] or a combination of Next Steps and Last Steps (n = 5 studies).[13,17,30-32]

Interventionist Type and Training

There was wide variability in interventionist discipline and training, and in many cases, there was inadequate information provided on the interventionist. Registered nurses were utilized as interventionists in 5 studies[23,33-35,39]; in another 5 studies, the interventionist was a nurse or an allied health staff member (social workers and chaplains).[22,25,27,28,37] Lay navigators were utilized in 1 study.[38] In 6 studies, the discipline of the interventionist was not specified or was unknown.[13,26,30-32,36] In 9 articles, it was specified that the interventionist received official RC training,[17,25-28,30-32,38] but it was noted in 1 study that not all facilitators were fully trained,[37] and another 6 articles did not specify whether and how facilitators were trained.[22,23,33,36,36,39]

Study Outcomes

Table 2 specifies the outcomes investigated in each study. There was significant heterogeneity in the outcomes employed across studies. The most commonly evaluated outcomes were patient–surrogate congruence in treatment choices (n = 8 studies),[23,27,28,30,31,33-35] patient and/or surrogate satisfaction with

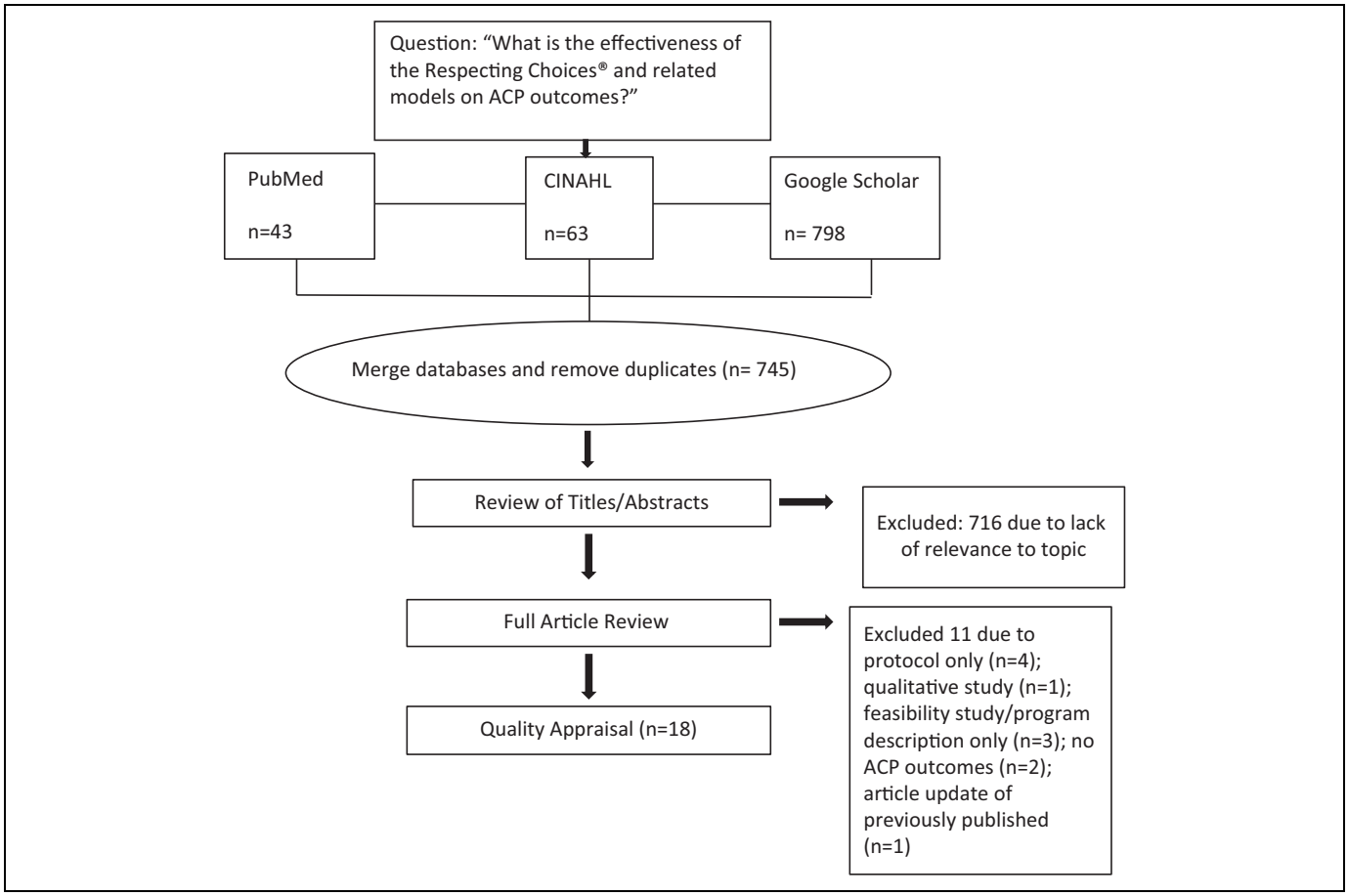

Figure 1. Respecting Choices.

the ACP intervention or process (n = 7 studies),[17,26-28,30,32,39] and AD completion rates (n = 5 studies).[13,17,32,36,37]

Risk of Bias in Included Studies

Table 3 summarizes the risks of bias identified in each study. The most frequent bias identified was selection bias (n = 14; 87.5%). Among the RCTs (including pilots), 1 study had noted differences between intervention and control groups that were not adjusted for statistically,[23] whereas several others did not specify whether there were significant differences between the 2 groups or did not provide enough information on the 2 groups.[27,28] In 1 study, the intervention group had a higher likelihood of previous ACP exposure,[35] which could strongly bias the outcome. In addition, among the observational studies, 2 compared participants to nonparticipants,[22,38] and in 1, there was a racial difference in participants who were offered the opportunity to participate.[38]

Performance bias was also a major issue for 13 of the 16 studies. The major issue contributing to performance bias was that the control group in the RCTs was generally only offered an educational pamphlet on ACP or nothing at all,[23,25-28,31-33,35] versus in person sessions with an interventionist received by the intervention group. One study offered a time and attention equivalent to the control group on topics other than ACP.[30] There were no comparative effectiveness studies directly comparing RC or a derivative model to another form of ACP intervention. In addition, completing an AD or a POLST was part of the intervention in 3 studies and yet AD and/or POLST completion was also measured as an outcome, making it an unavoidable confounder.[17,32,39]

Poor reporting made it difficult to assess measurement bias across the studies. In some studies, the pre- and postintervention measures were collected by research assistants other than the interventionist—but it was not always clear whether they were blinded.[30-32] In addition, 1 study measured outcomes twice for the intervention group (pre- and postintervention) but only once for the control group (if they did not receive anything).[27,28]

The reporting on attrition was not clear enough in 3 studies to determine the risk of attrition bias.[31-34] In 1 article, it was unclear whether an outcome was statistically significantly different between the intervention and control groups as *P* values were not reported.[25]

Evidence Synthesis

The goal of ACP is to improve communication about EOL preferences and ultimately to improve the rate of preference-concordant treatment. In addition, greater preference-

Table 2. Study Characteristics and Summary of Findings.

First Author, Year	Model and RC Step	Outcomes	Study Design	Sample	Measures	Results	Location	Interventionist
Briggs, 2004	PC-ACP: Next Steps	Knowledge of ACP, patient–surrogate congruence, decisional conflict, and quality of patient–clinician communication	Randomized control trial (RCT) stratified by diagnosis	N = 27 dyads; clients with heart failure, end-stage renal disease, or pre-open heart surgery	Statement of treatment preferences, treatment decision-making role preference, decisional conflict scale, knowledge instrument	Greater patient-surrogate congruence, decreased decisional conflict, higher rating of quality of patient–clinician communication in intervention group. No differences in ACP knowledge	La Crosse, Wisconsin	Nurse
Detering, 2010	Respecting Choices—adapted to Australia: Next Steps	Consistency of treatment with wishes, satisfaction with hospital stay; surrogate mental health post-bereavement	RCT	N = 309; 80+-year-olds admitted under internal medicine, cardiology, or respiratory	Chart review; post-death surrogate interview, Hospital Anxiety Depression Scale (HADS) for anxiety, depression	Higher ACP completion rate, greater likelihood of having wishes known and respected, higher satisfaction in intervention group	Australia	Nurse or allied health worker
Hall, 2014	PC-ACP: Last Steps	Number of patients with completed POLST, resident and surrogate satisfaction with process	Pilot, pre-/posttest	N = 8 dyads; assisted living residents with <1 year life expectancy, cognitively intact with surrogate available	Chart review; quality of patient–clinician communication about EOL care	All patients completed POLST form. 90% rated quality of interaction as positive	Minnesota	Nurses
Hammes, 2010	Respecting Choices: Next steps and Last Steps	AD prevalence, POLST prevalence, consistency of treatment with wishes	Retrospective, comparative, observational study comparing cohorts from 2007/2008 to 1995/1996	N = 940 (cohort 1: 540; cohort 2:400); adult decedents	Chart review	Greater AD prevalence in later cohort (90% vs 85%). Little difference in consistency of treatment with wishes	La Crosse County, Wisconsin	Unknown
Huang, 2016	Respecting Choices + motivational interviewing + health literacy adapted AD: First Steps	Satisfaction with ACP, knowledge of ACP, intent to complete AD	Pilot RCT, mixed-method	N = 30 dyads; ≥45 years; community-dwelling African Americans	RC program evaluation questionnaire, knowledge instrument, 1 question on intent to complete (Y/N)	No difference in intent to complete (100% both groups), no difference in knowledge	Deep south	Certified Respecting Choice facilitator
In der Schmitten, 2014	Respecting Choices—adapted to Germany: Next Steps and Last Steps	Incidence of new ADs, prevalence of ADs, incidence and prevalence of physician orders on life-sustaining treatment (German equivalent of POLST)	Cohort case–control study between regions (intervention and control)	N = 136 intervention (3 sites); 439 control (10 sites); nursing home residents	Chart review	Increased ACP completion, number of proxy designations, and documentation of code status in intervention sites	Germany	Trained nonphysician facilitators; trained primary care physician facilitators
Kirchhoff, 2010	PC-ACP: Next Steps	Knowledge about ACP, patient–surrogate congruence, satisfaction with process	RCT, stratified by site and diagnosis	N = 313; adults with congestive heart failure and end-stage renal disease with life expectancy <2 years	Knowledge about ACP tool, statement of treatment preferences, quality of patient–clinician communication (intervention only)	Greater congruence and knowledge in intervention than control. Intervention group highly satisfied (satisfaction not evaluated in control)	Wisconsin (La Crosse and Madison)	Nurses, social workers, and a chaplain
Kirchhoff, 2012	PC-ACP: Next Steps	Consistency between treatment and expressed wishes	RCT, stratified by site and diagnosis	N = 313; adults with congestive heart failure and end-stage renal disease with life expectancy <2 years	Phone interview with surrogate	No significant differences in consistency of treatment with wishes between 2 groups; greater dialysis withdrawal for end-stage renal disease patients in intervention group	Wisconsin (La Crosse and Madison)	Nurses, social workers, and a chaplain

(continued)

Table 2. (continued)

First Author, Year	Model and RC Step	Outcomes	Study Design	Sample	Measures	Results	Location	Interventionist
Lyon, 2009	Adapted DS-ACP + Lyon ACP Survey + 5 Wishes: Next Steps and Last Steps	Patient–surrogate congruence, decisional conflict, satisfaction with ACP process	RCT	N= 38 dyads; HIV+ adolescents and adult guardians	Statement of treatment preferences, Decisional Conflict Scale, Quality of Patient–Interviewer Communication Scale	Increased congruence, satisfaction and adolescent knowledge in intervention group; lack of clear reporting on decisional conflict	Washington DC and Memphis, Tennessee	Trained research assistant (discipline unspecified)
Lyon, 2013	RC + Lyon family-centered ACP survey + 5 wishes: Next Steps and Last Steps	Patient–surrogate congruence, decisional conflict, quality of communication	RCT	N = 30 dyads; adolescents with cancer and their adult guardians	Statement of Treatment Preferences, Decisional Conflict Scale, Quality of Patient–Interviewer Communication Scale	Greater patient–surrogate congruence in intervention group; adolescents felt better informed about ACP in intervention group; no difference in decisional conflict or quality of communication	Washington DC	Trained research assistant (discipline unspecified)
Lyon, 2014	RC + Lyon family-Centered ACP survey + 5 wishes: Next Steps and Last Steps	Quality of life, accessibility of ACP in chart, spirituality, satisfaction	RCT	N = 30 dyads; adolescents with cancer and their adult guardians	Satisfaction Questionnaire, Beck Anxiety and Depression Inventories, Pediatric Quality of Life Inventory, Spiritual Well-Being Scale, chart review	Intervention families were satisfied (no comparison to control group), anxiety increased in intervention group versus control over time; depression decreased in intervention versus control over time. 100% completion of 5 wishes document in intervention versus 0% in control. Increased spirituality in intervention	Washington DC	Trained graduate students (discipline unspecified)
Moorman, 2012	Respecting Choices: Next Steps	Social diffusion of RC: AD prevalence in those with residential access to La Crosse area health systems, those with social access and those with none	Secondary analysis of survey data—Wisconsin longitudinal survey	N = 5, 106; >65-year-old Wisconsin high-school graduates—all white	Dichotomous survey questions	High levels of ACP overall (55% living wills; 52% power of attorney, 74% informal discussions). Those with residential access less likely to have ACP. No evidence for social diffusion	Wisconsin	Unspecified
Pecanac, 2014	Respecting Choices: Next Steps	Prevalence of ADs; consistency between treatment and expressed wishes	Retrospective, comparative chart review of pre-RC implementation (2005-2007) and postimplementation (2008-2010)	N = 732; adult decedents who died in hospital (excluded emergency department deaths)	Chart review	Most decedents had ADs prior to hospitalization. No change in AD prevalence when examining all decedents or white decedents only. Significant increase in ADs in racial minorities post-RC implementation. No change in consistency between wishes and care provided	Milwaukee, Wisconsin	Chaplains, social workers, and ethicists
Rocque, 2017	Respecting Choices: First Steps (although population appropriate for Next Steps)	Number of documented ACP conversations; end-of-life health-care utilization	Mixed-method prospective evaluation	N = 8704; adult cancer patients	Chart review and claims data for hospitalizations, emergency department (ED) visits, intensive care (ICU) admissions, chemotherapy, and hospice use	Navigators initiated ACP discussions with 15% of patients. Decreased hospitalization rates in those who had ACP conversation. No difference in hospice. No significant difference in ED/ICU/chemotherapy use	Southern United States	Lay navigators
Schellinger, 2011	DS-ACP: Next Steps	Type of documentation related to ACP noted in electronic health record; health-care utilization	Longitudinal, comparative (participants vs nonparticipants)	N = 1894 (602 participants, 1292 nonparticipants); adults with heart failure	Chart review	31.8% of referrals participated. Participants has 94.3% ACP completion rate versus 24.8% of nonparticipants. No difference in hospital 30- or 60-day readmissions. Among decedents, increased hospice enrollment and longer hospice length of stay for those who participated	Minnesota and Wisconsin	Nurses and social workers

(continued)

Table 2. (continued)

First Author, Year	Model and RC Step	Outcomes	Study Design	Sample	Measures	Results	Location	Interventionist
Schwartz, 2002	Respecting Choices: Next Steps	Patient–surrogate congruence; knowledge on ACP; surrogate's comfort with role; patient preferences	RCT	N = 61 dyads; older adults	Medical Directive Questionnaire; Knowledge Questionnaire; Agent Comfort Questionnaire; Beliefs and Values Questionnaire	Increased congruence, knowledge and surrogate comfort in intervention group	Massachusetts	Nurse
Song, 2005	PC-ACP: Next Steps	Patient–surrogate congruence, knowledge on ACP; anxiety around ACP; decisional conflict	RCT	N = 32 dyads; clients from cardiothoracic surgery clinic	Statement of Treatment Preferences; Spielberger State Anxiety Inventory; Decisional Conflict Scale	Increased congruence in intervention group; no difference in anxiety or knowledge; decreased decisional conflict in intervention	La Crosse, Wisconsin	Nurse
Song, 2010	PC-ACP: Next Steps	Decisional conflict; patient–surrogate congruence; surrogate comfort with role; psychosocial well-being of dyad	RCT	N = 17 dyads; African-Americans with end-stage renal disease receiving dialysis	Statement of Treatment Preferences; Decisional Conflict Scale; Decision-Making Confidence Scale	Increased congruence in intervention group. Intervention group had greater preference for life-sustaining treatment than control group. No differences in decisional conflict or surrogate comfort or psychosocial well-being.	United States	Nurse

Abbreviations: ACP, advance care planning; AD, advance directive; DS-ACP, disease-specific ACP; PC-ACP, patient-centered ACP; POLST, Physician's Order for Life-Sustaining Treatment; RC, Respecting Choices

Table 3. Risk of Bias.[a]

Study	Selection Bias	Attrition Bias	Performance Bias	Measurement Bias	Reporting Bias	Overall Risk Judgment
Briggs	+	−	+	+	−	High
Detering	−	+	+	−	+	High
Hall	+	+	−	+	−	High
Hammes	+	−	−	?	−	Low
Huang	−	−	+	?	−	Moderate
In der Schmitten	+	+	−	+	−	Moderate
Kirchhoff 2010 and 2012	?	+	+	−	−	High
Lyon 2009	−	−	−	+	−	Low
Lyon 2013/2014	+	?	+	−	−	Moderate
Moorman	+	−	−	−	−	Low
Pecanac	+	−	−	?	−	Low
Rocque	+	−	−	+	−	High
Schellinger	+	−	+	+	−	High
Schwartz	?	?	+	+	−	High
Song 2005	+	−	+	+	−	High
Song 2010	?	?	+	−	−	High

[a](+) = positive bias, (-) = no identified bias, and (?) = lack of information.

concordant treatment is often linked to decreased EOL health-care utilization and this is seen as a benefit of ACP. Thus, there were 4 outcomes that we judged to be of key importance to this body of literature: the AD and/or POLST completion rate (incidence and/or prevalence), patient–surrogate congruence, consistency between treatment and expressed wishes, and EOL health-care utilization.

There were 5 studies that examined the incidence and/or prevalence of ADs as an outcome[13,17,32,36,37]—4 assessed this outcome via chart review and 1 measured it via self-report on survey questions. One study was an RCT, which included AD completion as part of the protocol[32] and 1 was a well-designed cohort case–control study with a high risk of bias.[17] Three of the 5 studies showed an increase in AD incidence and/or prevalence in the intervention group or postintervention.

Three studies measured POLST completion rate.[13,17,39] One was a well-designed cohort case–control study with a high risk of bias,[17] 1 was observational,[13] and 1 was a pretest–posttest study which included POLST completion as part of the study protocol.[39] All 3 studies demonstrated a positive impact of RC and derivatives on the prevalence of POLST. We conclude that there is low-level evidence that RC or derivative models positively impact the completion of ADs and POLST when compared to an inactive control when used in Caucasian populations.

There were 7 studies that examined the outcome of patient–surrogate congruence.[23,27,28,30,31,33-35] Of these, 6 measured it using the Statement of Treatment Preferences, whereas 1 utilized the Medical Directive Questionnaire.[33] These tools measure congruence by asking patients and surrogates separately to make choices in hypothetical scenarios. All of these were RCTs and all consistently demonstrated greater patient–surrogate congruence in the intervention group compared to the control group. We conclude that there is high-level evidence that RC or derivative models positively impact patient–surrogate congruence when compared to inactive control when used in Caucasian populations. There is low-level evidence (1 study)[34] for the same conclusion among African Americans.

There were 4 studies that examined the outcome of consistency between treatment and expressed wishes—3 with chart review,[13,25,37] whereas 1 utilized a phone interview with the family surrogate.[28] Two of these were RCTs[25,28] and 2 were retrospective chart reviews.[13,37] Of these, 1 (performed in Australia) found an increase in consistency in the intervention versus control group[25] and the other 3 (performed in the United States) found no differences in consistency of treatment with expressed wishes. We conclude that there is mixed evidence that RC and its derivative models have any effect on the consistency of EOL treatment with expressed patient wishes.

Only 2 studies examined health-care utilization,[22,38] both compared those who participated in ACP with those who did not. Both measured this utilizing chart review and/or claims data. One found no difference in hospitalizations, but greater hospice admission and longer hospice length of stay for those who participated.[22] The other found decreased hospitalization rates among participants with no significant differences for emergency department visits, intensive care stays, or chemotherapy use.[38] Both studies had a high risk of bias. We conclude that there is mixed, very low-level available evidence that RC and its derivative models have any effect on health-care utilization at the EOL.

Discussion

Respecting Choices and its derivative models have been widely implemented in Wisconsin and Minnesota. However, in synthesizing the published evidence, we found that the evidence for RC is not as strong as might be thought. For the immediate outcome of increasing AD and POLST completion, there is a low level of evidence in support of RC and derivative models. For the outcome of patient–surrogate congruence in

making choices in hypothetical scenarios, there is a high level of evidence in support of RC and related models among Caucasians (and low level of evidence among African Americans). However, for the long-term outcomes of AD and ACP on consistency of treatment with wishes and overall EOL health-care utilization, the evidence was mixed, inconclusive, and generally low quality.

Respecting Choices models are generally found to increase the likelihood that an AD or a POLST will be completed and that it will be able to be located in the patient's chart. The incidence and prevalence of ADs have been one of the most common indicators that health-care systems have used to evaluate their ACP programs.[41] This is not surprising, as having a written document is one of the easiest tools to measure the outcomes of the ACP process. It is somewhat unclear, however, which patients are likely to willingly participate versus those unwilling to participate. It is also unclear whether there is a subset of population that is more likely to benefit from the time and resource-intensive nature of the RC model.

Based on this review, the evidence that RC models increase patient-surrogate congruency is the strongest of the outcomes that were examined. The idea behind patient–surrogate congruence is that the better the surrogate knows the patient's wishes, the more effective they will be as a surrogate—and potentially, the more comfortable they will feel in the surrogate role. Like the presence of ADs, patient–surrogate congruence is relatively easily measured. Little is known about whether patient–surrogate congruence measured on hypothetical scenarios translates to more effective surrogate decisions when confronted with real-life decisions or whether surrogate comfort level is maintained amid real-life decisions. Given that individual preferences evolve over time and with illness and treatment exposure, it is unclear whether patient–surrogate congruence also evolves.[7-9] We must also note that there is little data on patient–surrogate congruence among other racial or ethnic groups besides Caucasians.

A major challenge to the use of ADs is the charge that they "fail" or do not work—either in protecting a patient's wishes at the EOL or in reducing unnecessary or futile health-care utilization at the EOL. Based on the reviewed evidence, RC and its derivative models are liable to the same charge. There is mixed, low-level evidence on the impact of RC on either the consistency of treatment with expressed wishes or overall EOL health-care utilization. This is not surprising, as a systematic review of how health-care systems evaluate ACP initiatives found this to be a weakness generally.[41] Further studies are needed to better examine whether ADs in general—and RC models in particular—can have a clinically meaningful difference in honoring patient choices and reducing unwanted treatment in the EOL.

Importantly, we note that RC models were never tested against another method of ACP. This is important as RC is a resource-intensive model and the program implementation fee can range from US$190 000. to US$500 000, making it difficult to scale the model.[42] Furthermore, there was some variance in which components of RC (eg, First Steps, Next Steps, and Last Steps) were tested. Further testing of RC is needed to determine which aspects of the model are most impactful—and for whom. In addition, further testing in diverse geographical regions of the United States and with other minority populations, such as Latinos and Asians, is needed.

Strengths and Limitations

Although we used a comprehensive search strategy with broad inclusion criteria, it is possible that relevant studies may have been missed. We utilized the criteria developed by the Cochrane Collaborative for assessing the risk of bias, but there is still some subjectivity involved in determining the risk of bias.[24] In addition, we focused on patient-/family-centered outcomes, which may or may not be relevant to various stakeholders. Due to scarcity of published evidence on RC model, we included RC and derivative models in this analysis. Future studies may focus specifically on the outcomes of the RC model as evidence accumulates.

Conclusion

The RC and derivative models of ACP likely increase patient–surrogate congruence on hypothetical EOL scenarios and are also likely to increase the prevalence of AD and POLST completion. However, there is not enough evidence that either the RC and derivative models or the completion of ADs and POLST actually change the quality of EOL care or the congruence between actual treatment received and patient expressed preferences. We urge that further testing of the RC and derivative models be conducted, particularly with a focus on outcomes that reflect quality of EOL care received (eg, consistency between care received and expressed preferences, health-care utilization, surrogate distress post death). The model should also be evaluated as part of comparative effectiveness studies, especially against lower cost models to see whether comparable ACP outcomes may be arrived at using low resource interventions.

Declaration of Conflicting Interests

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ORCID iD

Meredith A. MacKenzie, PhD, RN, CRNP, CNE http://orcid.org/0000-0002-9788-1320

References

1. Sudore RL, Lum HD, You JJ, et al. Defining advance care planning for adults: a consensus definition from a multidisciplinary Delphi panel. *J Pain Symptom Manage*. 2017;53(5):821-832.e821.

2. Mack JW, Cronin A, Taback N, et al. End-of-life care discussions among patients with advanced cancer: a cohort study. *Ann Intern Med*. 2012;156(3):204-210.
3. Bernacki RE, Block SD; American College of Physicians High Value Care Task Force. Communication about serious illness care goals: a review and synthesis of best practices. *JAMA Intern Med*. 2014;174(12):1994-2003.
4. Cosgriff JA, Pisani M, Bradley EH, O'Leary JR, Fried TR. The association between treatment preferences and trajectories of care at the end-of-life. *J Gen Intern Med*. 2007;22(11):1566-1571.
5. Hickman SE, Hammes BJ, Torke AM, Sudore RL, Sachs GA. The quality of physician orders for life-sustaining treatment decisions: a pilot study. *J Palliat Med*. 2017;20(2):155-162.
6. Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: The National Academies Press; 2015.
7. Danis M, Garrett J, Harris R, Patrick DL. Stability of choices about life-sustaining treatments. *Ann Intern Med*. 1994;120(7): 567-573.
8. Lynn J, Arkes HR, Stevens M, et al. Rethinking fundamental assumptions: SUPPORT's implications for future reform. Study to Understand Prognoses and Preferences and Risks of Treatment. *J Am Geriatr Soc*. 2000;48(5 suppl):S214-S221.
9. Fried TR, Byers AL, Gallo WT, et al. Prospective study of health status preferences and changes in preferences over time in older adults. *Arch Intern Med*. 2006;166(8):890-895.
10. Gundersen Health System. Respecting Choices®—Person Centered Care. http://www.gundersenhealth.org/respecting-choices/. 2017. Accessed March 14, 2017.
11. Prendergast TJ. Advance care planning: pitfalls, progress, promise. *Crit Care Med*. 2001;29(2 suppl):N34-N39.
12. Hammes BJ, Rooney BL, Gundrum JD, Hickman SE, Hager N. The POLST program: a retrospective review of the demographics of use and outcomes in one community where advance directives are prevalent. *J Palliat Med*. 2012;15(1):77-85.
13. Hammes BJ, Rooney BL, Gundrum JD. A comparative, retrospective, observational study of the prevalence, availability, and specificity of advance care plans in a county that implemented an advance care planning microsystem. *J Am Geriatr Soc*. 2010; 58(7):1249-1255.
14. Hammes BJ, Rooney BL. Death and end-of-life planning in one midwestern community. *Arch Intern Med*. 1998;158(4):383-390.
15. Korfage I, Rietjens J, van der Heide A. ADVANCE—advance care planning; an innovative palliative care intervention to improve quality of life in cancer patients—a multi-centre cluster randomized clinical trial—FP7 project. *Impact*. 2017;2017(4): 37-39.
16. Barehmi Z. Coalition to Transform Advanced Care. C-TAC Launches Service Affiliate C-TAC Innovations, Which Includes Respecting Choices®. Joint Press release from The Coation to Transform Advanced Care and The Gundersen Health System. 2016. http://www.thectac.org/2016/09/c-tac-launches-service-affiliate-ctac-innovations-includes-respecting-choices/. Accessed July 15, 2017.
17. In der Schmitten J, Lex K, Mellert C, Rotharmel S, Wegscheider K, Marckmann G. Implementing an advance care planning program in German nursing homes: results of an interregionally controlled intervention trial. *Dtsch Arztebl Int*. 2014;111(4):50-57.
18. Moher D, Liberati A, Tetzlaff J, Altman DG; PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med*. 2009;6(7): e1000097.
19. Brozek JL, Akl EA, Alonso-Coello P, et al. Grading quality of evidence and strength of recommendations in clinical practice guidelines. Part 1 of 3. An overview of the GRADE approach and grading quality of evidence about interventions. *Allergy*. 2009; 64(5):669-677.
20. Brozek JL, Akl EA, Compalati E, et al. Grading quality of evidence and strength of recommendations in clinical practice guidelines: part 3 of 3. The GRADE approach to developing recommendations. *Allergy*. 2011;66(5):588-595.
21. Brozek JL, Akl EA, Jaeschke R, et al. Grading quality of evidence and strength of recommendations in clinical practice guidelines: part 2 of 3. The GRADE approach to grading quality of evidence about diagnostic tests and strategies. *Allergy*. 2009;64(8): 1109-1116.
22. Schellinger S, Sidebottom A, Briggs L. Disease specific advance care planning for heart failure patients: implementation in a large health system. *J Palliat Med*. 2011;14(11):1224-1230.
23. Briggs LA, Kirchhoff KT, Hammes BJ, Song MK, Colvin ER. Patient-centered advance care planning in special patient populations: a pilot study. *J Prof Nurs*. 2004;20(1):47-58.
24. Higgins JPT, Altman DG, Gøtzsche PC, et al. The Cochrane Collaboration's tool for assessing risk of bias in randomised trials. *BMJ*. 2011;343:d5928.
25. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ*. 2010;340:c1345.
26. Huang CH, Crowther M, Allen RS, et al. A pilot feasibility intervention to increase advance care planning among African Americans in the deep south. *J Palliat Med*. 2016;19(2):164-173.
27. Kirchhoff KT, Hammes BJ, Kehl KA, Briggs LA, Brown RL. Effect of a disease-specific planning intervention on surrogate understanding of patient goals for future medical treatment. *J Am Geriatr Soc*. 2010;58(7):1233-1240.
28. Kirchhoff KT, Hammes BJ, Kehl KA, Briggs LA, Brown RL. Effect of a disease-specific advance care planning intervention on end-of-life care. *J Am Geriatr Soc*. 2012;60(5):946-950.
29. Bakitas M, Lyons KD, Hegel MT, et al. Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: the Project ENABLE II randomized controlled trial. *JAMA*. 2009;302(7):741-749.
30. Lyon ME, Garvie PA, McCarter R, Briggs L, He J, D'Angelo LJ. Who will speak for me? Improving end-of-life decision-making for adolescents with HIV and their families. *Pediatrics*. 2009; 123(2):e199-e206.
31. Lyon ME, Jacobs S, Briggs L, Cheng YI, Wang J. Family-centered advance care planning for teens with cancer. *JAMA Pediatr*. 2013;167(5):460-467.
32. Lyon ME, Jacobs S, Briggs L, Cheng YI, Wang J. A longitudinal, randomized, controlled trial of advance care planning for teens

with cancer: anxiety, depression, quality of life, advance directives, spirituality. *J Adolesc Health*. 2014;54(6):710-717.
33. Schwartz CE, Wheeler HB, Hammes B, et al. Early intervention in planning end-of-life care with ambulatory geriatric patients: results of a pilot trial. *Arch Intern Med*. 2002;162(14):1611-1618.
34. Song MK, Donovan HS, Piraino BM, et al. Effects of an intervention to improve communication about end-of-life care among African Americans with chronic kidney disease. *Appl Nurs Res*. 2010;23(2):65-72.
35. Song MK, Kirchhoff KT, Douglas J, Ward S, Hammes B. A randomized, controlled trial to improve advance care planning among patients undergoing cardiac surgery. *Med Care*. 2005; 43(10):1049-1053.
36. Moorman SM, Carr D, Kirchhoff KT, Hammes BJ. An assessment of social diffusion in the Respecting Choices advance care planning program. *Death Stud*. 2012;36(4):301-322.
37. Pecanac KE, Repenshek MF, Tennenbaum D, Hammes BJ. Respecting Choices® and advance directives in a diverse community. *J Palliat Med*. 2014;17(3):282-287.
38. Rocque GB, Dionne-Odom JN, Sylvia Huang CH, et al. Implementation and impact of patient lay navigator-led advance care planning conversations. *J Pain Symptom Manage*. 2017;53(4): 682-692.
39. Hall NA, Jenson CE. Implementation of a facilitated advance care planning process in an assisted living facility. *J Hosp Palliat Nurs*. 2014;16(2):113-119.
40. Belle SH, Burgio L, Burns R, et al. Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: a randomized, controlled trial. *Ann Intern Med*. 2006;145(10): 727-738.
41. Biondo PD, Lee LD, Davison SN, Simon JE. How healthcare systems evaluate their advance care planning initiatives: results from a systematic review. *Palliat Med*. 2016;30(8): 720-729.
42. Belisomo R.Respecting Choices: Financial Facts and Figures. *Voices in Bioethics*. 2014. www.voicesinbioethics.net/newswire/2014/09/05/respecting-choices-financial-facts-and-figures. Accessed August 27, 2017.