Outline of this Presentation

1. Lessons from the past
   • What we learned from the SUPPORT Trial
   • Literature Review on Advance Directives
2. Summary of two recent, review articles
   • Effects of ACP on end-of-life care
   • RC: A systematic review
3. What else do we know?
4. What new research is underway?
5. What research is still needed?
**1. Lessons from the Past**

SUPPORT: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment.

- SUPPORT was a multi-site (5), randomized control trial to test if improved information for the treating physician about an ICU patient’s preferences and prognoses would improve the quality of end-of-life care.

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**SUPPORT Assumptions**

1. **Standard Assumption at that time:** Outcomes are driven by baseline characteristics, i.e., disease and physiology

2. SUPPORT researchers believed that this was short sighted and that outcomes were driven by baseline characteristics and decisions-making about treatment.

3. SUPPORT developed an intervention to improve decision-making.
**SUPPORT Intervention**

- Improved understanding of prognoses.
- Improved understanding of current and past preferences of the patient.
- Assist patient and family so they can make choices that aligned with patient preferences.

- To achieve these outcomes a study interventionalist, an RN, would gather information and provide it to the treating physician.

**SUPPORT Outcome?**

- No improvement in care in the intervention group when compared to baseline data or the control group.
- This study is one of the most important research failures in medicine in the ’90s.
- We need to learn from this failure if we want to improve care of seriously ill patients.
According to the SUPPORT PI, Joanne Lynn, MD, we learned the following:

- “...improving patient-physician communication cannot ameliorate shortcomings in care; improvement requires restructuring the entire environment.”
- “...a more systematic, far-reaching, and deeply seated plan to restructure the hospital environment is needed.”

What Did SUPPORT Teach Us?

Lynn J; Arkes, HR; Stevens, M et. al. Rethinking fundamental assumptions: SUPPORT's implication for future reform. JAGS; 48:S214-S221, 2000.
Rand Report to Congress: 
Literature Review on Advance Directives

- The US Congress authorized a review of the literature focused on advance care planning (ACP)/Advance Directives.
- The Rand Corporation was awarded the contract.
- 365 articles and reports were cited in the review.
- In 2007, a review of the ACP literature was published, looking at evidence in print between 1990 – 2007.

Central Conclusion: Report to Congress

"Simple, single-component consumer education interventions designed to increase knowledge of, or completion of ADs were mostly unsuccessful, or were only modestly successful. Single-component interventions tended to result in low AD completion rates, especially for interventions without an educational component or for mailed forms alone. Furthermore, few of these educational interventions were shown to decrease the use of life-sustaining treatments. Studies of more structured and/or facilitated end of life planning interventions with healthy, chronically ill, and seriously ill ambulatory geriatric patients and their caregivers demonstrated more promising, though modest results. Interventions were more successful when severely ill patients were targeted and when multi-component, longitudinal approaches were used—that is, interventions using educational materials combined with repeated treatment preference discussions during clinical encounters over time and with enhanced accessibility of the documentation of patient wishes when needed. Only multi-faceted interventions (e.g., education in combination with reminders and performance feedback) increased the frequency of physician-initiated AD discussions with patients."
2. Summary of Two Review Articles

The Effects of Advance Care Planning on End-of-Life Care: A Systematic Review.

This reviewed looked at 113 articles. Studies included:
- Described effectiveness of advance care planning
- Were quantitative
- Reported patient and utilization outcomes
- Included intervention and observation with a control group
- Published in English between 1/2000 to 12/2012


Conclusions About Use of Advance Directives

- Advance directives were associated with reduced frequency of feeding tubes, but not with other medical care or “...symptom burden, quality of life/quality of dying or satisfaction of care.”
- “...it seems unlikely that they (advance directives) have a substantial impact on patient-centered end-of-life care and satisfaction of care.”
Conclusions About Complex Interventions

“Complex ACP interventions were found to result in an increased frequency of out-of-hospital and out-of-ICU care and increased compliance with patient’s end-of-life wishes and satisfaction with care. We did not find clear results with respect to medical care, except for a tendency towards an increased use of hospice and palliative care. In a small majority of studies, psychosocial measures were positively effected by ACP.”

Summary of Two Review Articles

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

- After exhausted search, the authors identified 18 articles from 16 studies that reported outcomes of the RC and derivative models.
- 9 were randomized control trials, 6 were observational, 1 was pre-post test.

Outcomes Considered in Review

- Increase in completion of ADs or POLST forms.
- Pt/surrogate concurrence in making choices in specific situations.
- Long-term outcomes regarding consistency of preference being honored and its effect on overall health utilization.

Conclusion of Reviewers

Strong evidence that RC increases:

1. Congruence between patient and surrogates’ understanding of patients’ values & goals
2. Prevalence of AD and POLST completion

Still need more evidence that RC:

- Actually improves EOL care
- Leads to congruence between treatment and preferences
This Review has some Important Flaws

- Most importantly, the authors fail to see that most studies reviewed did not test the RC model (implementation of all 4 elements), but rather tested only one stage of facilitation for short term outcomes.
- A few studies were missed...the use of RC in these studies was difficult to see.
- Incorrectly described design and outcomes in some studies.
- Incorrectly ascribed stage of planning in some studies.
- Excluded practical clinical trials reported in white papers and did not assess evidence for Respecting Choices to evidence from other programs.

Research on Full RC Model

Three studies implemented the full RC model:
1. Hammes, LADS I and II...retrospective (community)
2. Detering, Impact of ACP...RCT (Hospital)
3. In der Schmitten, cohort case control (Regional group of SNFs)

- All of these studies showed an increase in written plans.
- 1 and 2 show increase in wishes known and honored and decrease in utilization of hospital services.
- Study 2 showed strong positive emotional impact on family member involved in the planning process.
Review Authors Recommend

1. More research...especially comparative effectiveness trials...especially against “lower cost models.”
2. Evaluating if use of RC leads to:
   a) preferences being honored
   b) lower utilization of health resources, and
   c) positive emotional outcomes for loved ones

3. What Else Do We Know?

A report of outcomes from a full implementation:
*Implementation at the Austin Health in Melbourne, Australia...one of Victoria’s largest public hospitals.*

- Baseline data in 2001: 10% of inpatients had poorly created care plans and 14.3% had completed a power of attorney (medical or financial).
- After full implementation of RC in 2003: 306 inpatients were followed.
  - 47% were introduced to ACP
  - 70% expressed preferences recorded in their medical record with 27% completing a formal document
  - Of those who died, 95% had their preferences honored
3. What Else Do We Know?

A report of outcomes after a full implementation:
“Final Evaluation of the Community Implementation of the Respecting Patient Choices Program.”

- Involved 16 residential age care facilities in Melbourne, Australia for 1 year
- Outcomes:
  - Residents and families were willing to have planning conversations
  - 51% of residents during the first year implementation were introduced to program
  - 52% of those introduced completed a plan
  - 90% of plans requested a palliative approach to care
  - Of the 161 residents who died, 58% were introduced and 89% of them had documented preferences
  - 100% had preferences honored and 88% died in the residential facility
  - Residents who died, but did not have a plan were 2.5 x more likely to die in hospital

3. What Else Do We Know?

Economic impact analysis of an end-of-life programme for nursing home residents.

- Project Care was introduced in 7 nursing homes to provide advance care planning and palliative care for residents at risk of dying within 1 year in Singapore.
- Outcomes:
  - Residents in Project Care had substantially lower cost of care in the last 3 months of life because of fewer hospital admissions and shorter lengths of stay in the hospital

Reducing Disparities in the Quality of Palliative Care for Older African Americans through Improved Advance Care Planning (EQUAL ACP)

In a PCORI-funded study, the principal investigator, Kimberly Johnson, MD, MS, of Duke University, will conduct a comparative effectiveness trial to determine which of 2 interventions will improve the quality of palliative care for older African Americans. The focus of the study is important because African Americans are less likely than Caucasian Americans to participate in advance care planning (ACP) and receive lower-quality palliative care.

The 2 interventions are these: a structured ACP approach (Respecting Choices® (RC)) or a patient-guided, self-management approach (Five Wishes). The study will be conducted in 5 states at 10 different clinical sites, which will be randomly assigned to deliver one intervention or the other to participants. The study plans to enroll 800 older adults and their caregivers, half of whom will be African American. The RC arm of the study will use the First Steps® (FS) ACP process for people with a chronic illness. The study is set to end in September 2022.

Status: This project is underway and is in the first year.

Patient-centered and efficacious advance care planning in cancer: the PEACe comparative effectiveness trial

PI: Yael Schenker, MD; University of Pittsburg

The research project is a comparative effectiveness trial of two formats of advance care planning (ACP) to improve patient-centered care near end of life (EOL). The investigators seek to determine whether in-person facilitated ACP (Respecting Choices First Steps) or web-based ACP (PREPARE for your care) is the better approach to improve treatment decisions near EOL and ensure patients' wishes are honored.

Status: This study has been reviewed and scored. Funding is expected and should begin in early 2019.
4. What Research is Starting or Coming?

Health Equity: Advance Care Planning for Spanish Speaking Teens with Cancer

PI: Maureen Lyon, Ph.D. National Children's Medical Center

Spanish speaking adolescents and families have been excluded from pACP research. To fill this gap in knowledge and practice this research will allow us to:

1. Create a culturally sensitive Spanish version of the FAmily C Entered pediatric Advance Care Planning (FACE pACP) using a process of community engagement, which has been successful in earlier adaptations. We will conduct this study at Children’s National in Washington, D.C. where 40% of our adolescent cancer patients are Hispanic/ Latino (15% Mexican, 7% Puerto Rican, 2% Cuban, 33% Salvadoran, 3% Dominican, 8% Guatemalan, and 33% Other).

2. Determine if Hispanic/Latino families find the FACE-TC Spanish intervention acceptable, doable and safe.

3. Test with 30 Spanish speaking adolescents living with cancer and their families in a pilot, randomized clinical trial, if participants randomized to FACE-TC Spanish will report increased agreement in treatment preferences, increased communication, decreased suffering, and improved quality of life, compared to those who receive treatment as usual.

Status: Research/project has been funded by the National Cancer Society.

4. What Research is Starting or Coming?

POLST Facilitation in Community Dwelling Older Adults

PI: Alexia Torke, MD, MS; Indiana University School of Medicine

The research will evaluate a systems based approach to ACP for a population of high risk older adults, to ensure that quality decisions take place, leading to POLST documents that are completed and available when needed to guide medical care. We have developed and pilot tested an approach to facilitate high quality Last Steps ACP conversations for community dwelling older adults. We propose to test this high quality ACP intervention in a randomized, controlled trial of 438 patients.

Status: This study has been reviewed and scored. Funding is likely and would begin in 2019.
1. **Large, Practical Clinical Trial**: A full scale, rapid, and comprehensive implementation of the whole RC program with clear, meaningful outcomes in a large, diverse population.

2. **Evaluation of how to better determine the true values and goals of an individual**: We all now seem to agree that the technical completion of an AD is not that helpful…the mere completion of a form. We need something like a) informed decision-making/planning and b) conversations that include the “family.”
   
a) Can these outcomes be adequately achieved by a conversation guide or an online decision guide?
b) Can certain populations be helped by a self-directed approach, but other populations or individuals need more personal assistance?

3. **How do we best achieve a cultural change so person-centered care is the norm**: To accomplish knowing and honoring it is essential to change behaviors…behaviors of people receiving medical care and those who provide it. Several popular, current programs are focused only on the education of providers or on the engagement of communities. Can these strategies, in themselves, be successful to create person-centered care?

4. **Does RC ACP facilitation have more benefits than creating an effective plan?** Evaluate if RC facilitation may also have one or more of these benefits:
   
a) Does it help create capacity in relationships to have better, ongoing discussions about what matters most?
b) Does it deepen interpersonal relationships and help create a better sense of well-being?
c) Does it provide an opportunity of individuals and their families to “rehearse” complex medical decisions so they are better able to actually make these decisions when they arise?

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**5. What Research is Still Needed? A Few Ideas...**

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*Respecting Choices*"