

The STAMP Trial: Increasing Engagement in ACP and Lessons Learned from Partnering with Community Ambulatory Practices

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October 22, 2021

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Funding and Disclosures

Supported by: R01 NR016007 and P30 AG21342

I have no conflicts of interest

Outline

Rethinking the purpose
and process of ACP

ACP as a health behavior

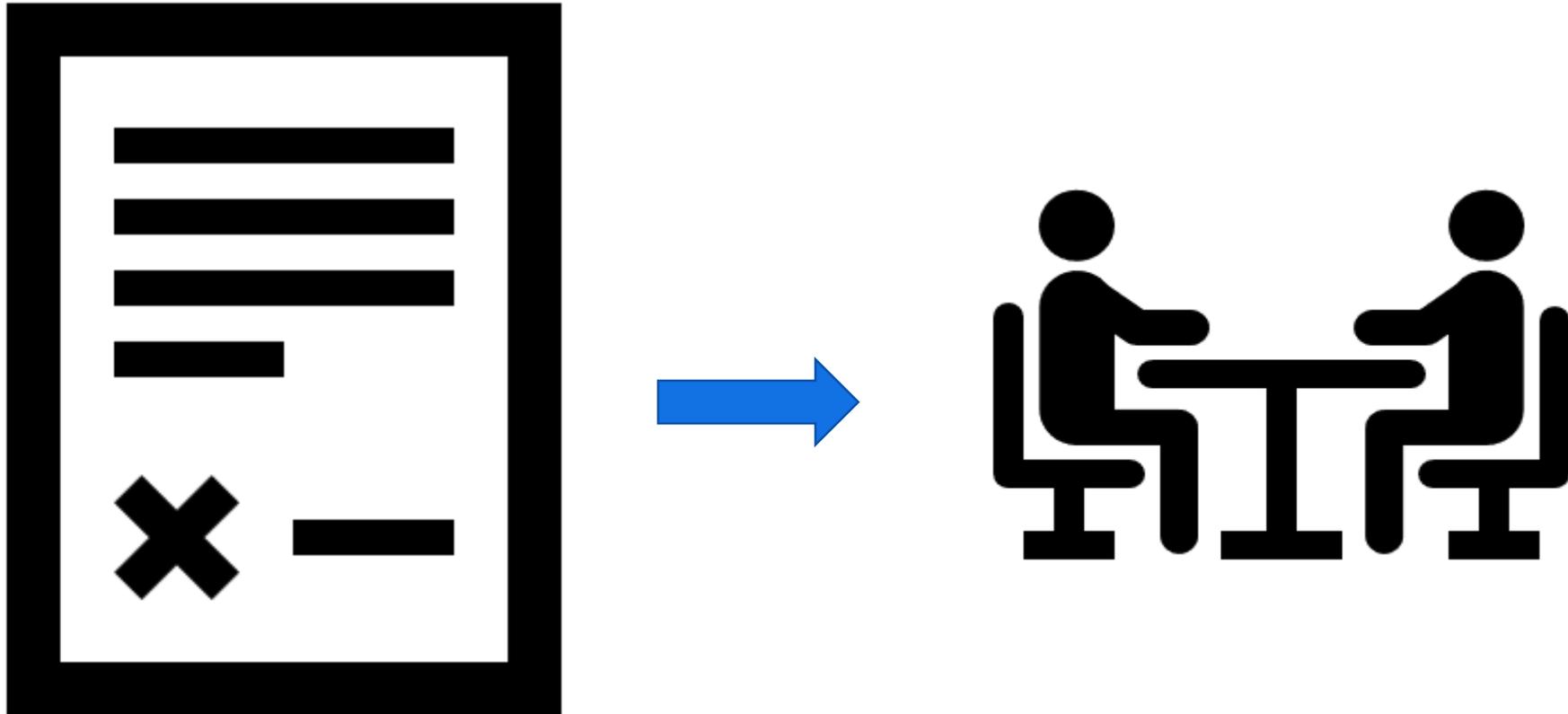
Trial results, challenges,
and lessons learned

STAMP

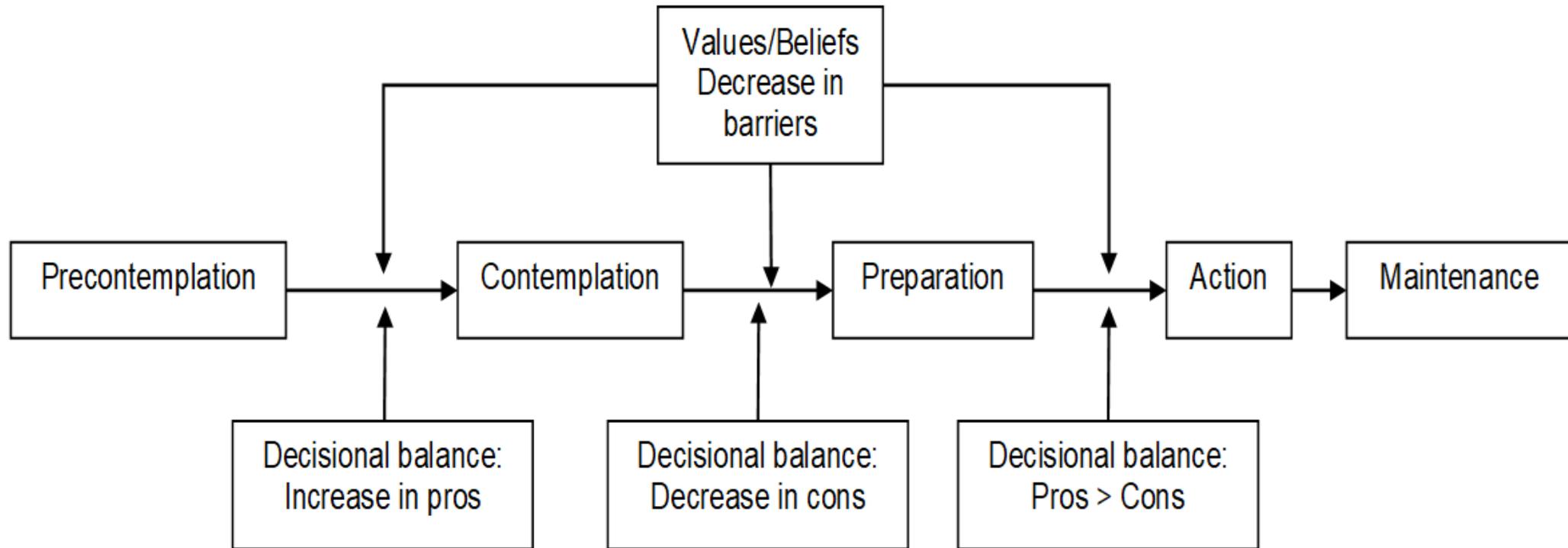
**SHARING & TALKING
ABOUT MY PREFERENCES**

ACP as Communication

Preparing for “In-the-moment” decision making



ACP as a Health Behavior





My Personal Report for Advance Care Planning

What is Advance Care Planning?

- Preparing you and your loved ones for making medical decisions in the future if you cannot speak for yourself.
- Taking control of your own healthcare – getting your medical house in order– taking the burden off of your loved ones.
- To do this, you:
 - Decide how you feel about balancing quality versus quantity of life, including the use of machines to prolong life.
 - Put a plan in place, so that you can get the kind of care you want.

What are the Steps of Advance Care Planning?

- Choose the person you think can best make healthcare decisions for you if you were not able.
- Talk to this person about your views on quality versus quantity of life and other wishes you may have about the care you would and would not want to receive if you were very sick.
- Fill out both a living will and a healthcare agent form.
- Make sure that both your living will and healthcare agent forms are in your electronic medical record.

Why do I need to do Advance Care Planning?

- When people get very sick, they often cannot make or state their own decisions.
- While most of us hope to die in our sleep, the fact is that people can get sick in unexpected ways that need hard decisions to be made.
- Doing this before you must face hard medical situations can be easier than waiting until you get sick.

What if it is too hard to think about getting very sick and dying?

- Remind yourself that making an Advance Care Plan can ease the burden for your loved ones.
- You can do this in small steps. Many people find that doing this isn't as bad as they imagined.

How Ready Are You?

This figure shows you how ready you are to do each of these steps towards your Advance Care Plan.



Your forms are:	at MD Office	in Medical Record
Healthcare Agent	-	-
Living Will	✓	-

You told us that you are:

- Last time you were not ready to talk to your loved ones about quality versus quantity of life, and now you are thinking about talking with them. That's progress!
- Last time you were not ready to name your healthcare agent, and now you are thinking about it. That's great!
- Just like last time, you have completed your living will.

Good for you for finishing one of the steps toward your Advance Care Plan and for getting ready to take some more steps. Moving forward with any of these steps will help you keep making progress. Since you have already started, you may find that the next steps get easier.

How Planning Can Help You



People who have done their plan tell us these benefits are important to them. Notice how many of these are also important to you:

- You would be taking charge of what happens to you in the future.
- You would be getting important affairs in order.
- You would feel more confident that you would get the healthcare that you would want.
- Your loved ones will be less stressed making decisions when they know your wishes.

Next Steps For You



Since you are thinking about/planning on talking to your loved ones about quality versus quantity of life and naming a healthcare agent, here are a few things you can do to help you move forward:

- Plan ways you can ask someone to be your healthcare agent. **Page 3** in the booklet, *Participating in Advance Care Planning: Part 2* gives you ideas for how you can start the conversation.
- You can also give the pamphlet, *A Guide for Surrogate Decision Makers* to the person you would like to be your agent.
- Look at **page 5** of the booklet for tips about how to start a conversation with your agent about your values and wishes.
- Also ask yourself the questions on **page 6** of the booklet and think about your answers. These will help you be very clear about your values and wishes.
- Make your healthcare agent official by naming that person on the healthcare agent form.
- Remind yourself that, by taking these steps, you are reducing the burden on your loved ones.

Having already completed your living will forms, you have already thought some about how you would want to be taken care of if you got very ill. Also, you are already familiar with many of the things you will need to do to complete your healthcare agent form.

- If you talk to your loved ones about what you want, they will know how to make decisions for you. This is because the doctors are probably going to

ask them to make decisions about your care if you cannot speak for yourself. People tell us they feel less stressed during and after these decisions if they have already had these conversations.

- Completing the healthcare agent form will then make it clear to the doctors whom they should ask to make the decisions.

Since you have filled out your living will and brought it to your doctor's office, you only have to do one more thing to make sure this form will be there when needed. This is to make sure that the form has been put into your medical record. It's important to do this because your doctor's office has to deal with so much paper. It's up to you to check to make sure that the forms are where they need to be. Here is how you can get this done:

- Make a time to call your doctor's office.
- Ask to have someone check to make sure that your form has been put into your medical record.

Your Summary



Thank you for reading this report about Advance Care Planning. We hope you have found it helpful in providing some support and sparking new ideas about how care planning can help you. The booklets have more information and stories that may answer any questions you may still have. When you're ready, taking some of the next steps towards your Advance Care Plan can help you take control of your medical care and take care of your loved ones at the same time.



Your Life, Your Values, Your Choices
Putting Your Health Care House In Order

Participating In Advance Care Planning: Part 1

Yale SCHOOL OF MEDICINE

THE UNIVERSITY OF RHODE ISLAND

All photographs are for illustrative purposes only and the people depicted are models.

ABC # 12052102/12 | Funding Source: NIA/NIH R21AG027791

ACP is not for me because...

I'll always be able to make my own decisions.

As you probably know from your own family and friends, when people get very sick, they sometimes can't speak for themselves. You never know when this may happen to you, so you need to have a plan in case it does.

My loved ones already know what kind of treatment I want.

Even if you think your loved ones know what you want, they need to hear it from you. This will make it easier on them down the road. It's also important to fill out the living will and health care proxy forms to remind your loved ones what your wishes are and who is in charge of your care if you are unable to speak for yourself.

The doctors wouldn't use machines on me if I were old and dying.

If you don't have a living will or health care proxy, the doctor is probably going to do everything possible to keep you alive for as long as possible, no matter how old and sick you are.

If I fill out a form, the doctors might take me off life-support sooner than I want.

ACP can help you get all the care you want. You can use the forms and conversation with your loved ones to make sure your wishes regarding treatment are clear.



“We all knew what we had to do.”



Mrs. Kramer is able to rest easy about the difficult decisions she had to make regarding her husband's medical treatment. He had a weak heart with

heart failure and fluid on his lungs. When he became increasingly short of breath, she took him to the emergency room. A doctor there told her and her family that things were not going well and asked if they wanted to put him on a respirator (breathing machine). “We told him no, because my husband and I talked about it all the time and he had said he

didn't want it,” said Mrs. Kramer. Her two daughters-in-law and sons were with her and they supported her decision. Her husband was admitted to a room in the hospital, where he got treatment to make him comfortable. He mostly slept over the next few days, and he died peacefully at the end of the week, with his family by his side.

Even with her preparation, it came as kind of a shock to Mrs. Kramer to have to make the decision and tell the doctors not to use the breathing machine. “It happened so fast,” she said. “I didn't know the doctor who came out to ask me.” But she knew that having talked to her husband and children about this in the past made their ordeal a lot easier. “My sons and daughters-in-law went right along with me,” she said. “We all knew this was what we had to do.”

How ready are you to choose a health care proxy?

I'm thinking about doing this.

Think about who you want to be your health care proxy. Consider all of the people who are close to you. Don't just include family, but also close friends and other important people in your life.

Now think about who could make good decisions for you. This should be someone who:

- Understands your wishes.
- Can separate their feelings from what you want.
- Will be available in an emergency. It is best if this is someone who can talk to your doctors directly.
- Doesn't have their own health problems, so they will be available in the future.

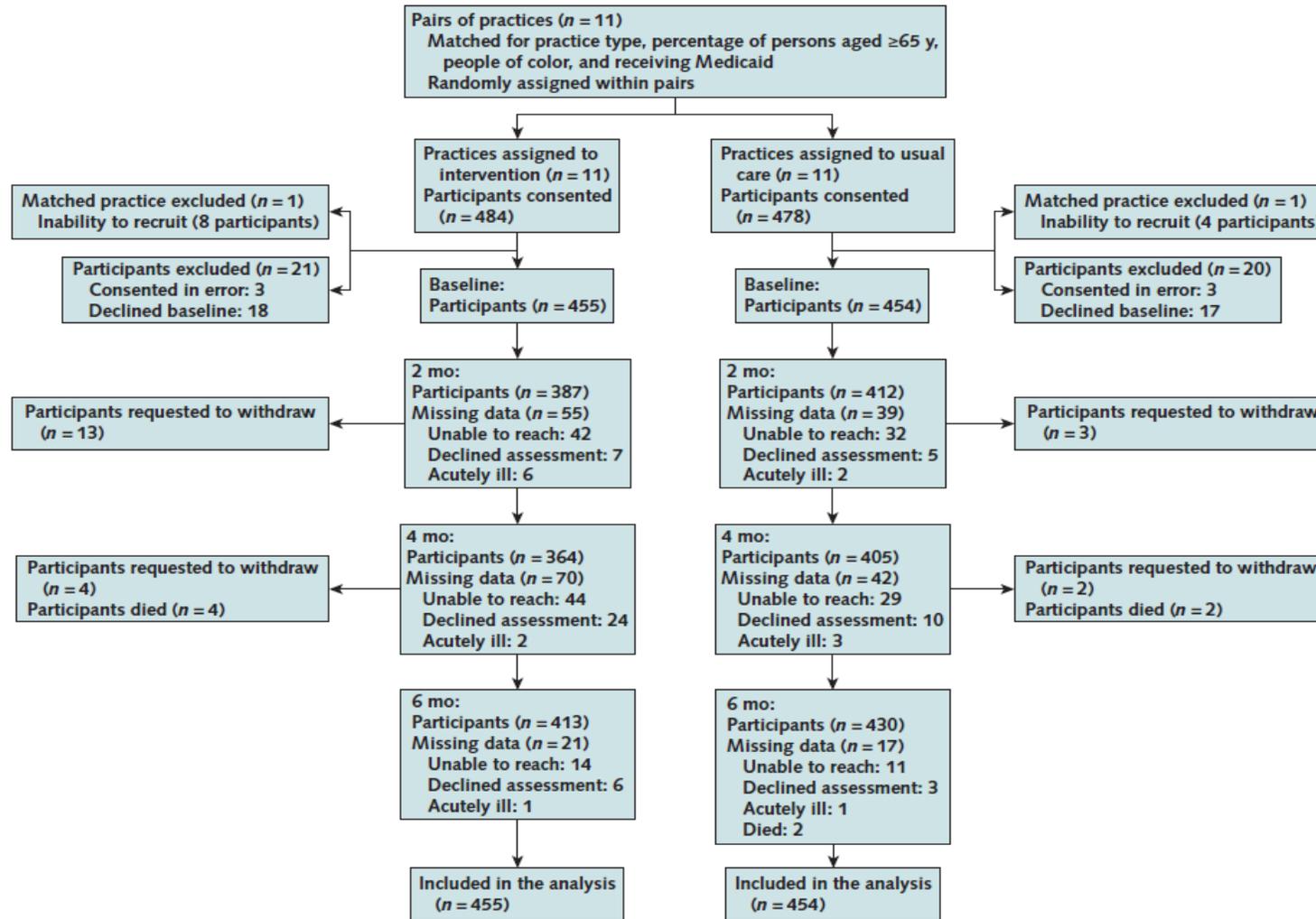
I'm ready to do this.

Once you know who you want as your health care proxy, you need to ask that person. You can say something like:

I would like to talk to you about something very important to me. I need someone who can help my doctors make the best decisions for me if I am in an accident or so sick that I can't make them myself. Would you be willing to do this for me?



Flow of Practices and Participants in the Study



Primary Results

Outcome	Participants Included in the Analysis, n*	Predicted Probability of Completion (95% CI), %†	Risk Difference (95% CI), percentage points‡	Adjusted Risk Difference (95% CI), percentage points‡
Completion of all advance care planning activities			5.9 (1.4 to 10.5)	5.2 (1.6 to 8.8)
Intervention	455	14.1 (11.0 to 17.2)		
Usual care	454	8.2 (4.9 to 11.4)		
Completion of a living will			8.2 (1.4 to 15.0)	6.5 (0.01 to 12.8)
Intervention	347	28.5 (24.5 to 32.6)		
Usual care	334	20.4 (15.0 to 25.7)		
Assignment of a health care agent			13.3 (6.6 to 20.1)	12.2 (2.8 to 21.5)
Intervention	372	32.8 (30.0 to 35.5)		
Usual care	349	19.5 (13.3 to 25.7)		
Communication about quality versus quantity of life			7.0 (−4.7 to 18.8)	2.8 (−7.9 to 13.5)
Intervention	151	61.6 (52.6 to 70.6)		
Usual care	165	54.5 (46.9 to 62.1)		

Challenges

Recruitment

- Recruitment of practices required hands-on effort.
- Recruitment at each practice required unique approach.

Review

Suspicious of whether our results were generalizable

- Reviewers wanted denominators
- If we could give them denominators, we would not have been in “typical” practices

Analysis

- Clustering, covariates, risk rather than odds
- Missing data

More Challenges

Timeframe

I wrote the first grant related to this work in 2005!

- Work split into multiple grants: R01, then R21, then another R01

Software development

The price of sustainability

- Using a proprietary system for the intervention

Lessons Learned

Cluster RCTs

- Will try very hard not to do another one!
- Complexities at every level

Missing data

- Will put majority of resources toward prevention

Software

- Will avoid proprietary companies