Cyberseminar Transcript

Date: August 9, 2017

Series: HSR&D Career Development Award Enhancement Initiative

Session: The Role of Family Caregiving in Chronic Illness

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Molly: And we are at the top of the hour now, so I’d like to introduce our speaker. Presenting for us today, we have Ranak Trivedi. Dr. Ranak Trivedi. She’s a core investigator at the Center for Innovation to Implementation, and an assistant professor in the department of psychiatry and behavioral sciences at Stanford University. And without further ado, Dr. Trivedi, are you ready to share your screen?

Dr. Ranak Trivedi: I am.

Molly: Okay, you should have that pop-up now.

Dr. Ranak Trivedi: One second. Do you see, wait.

Molly: Works perfect.

Dr. Ranak Trivedi: Perfect? Okay.

Molly: Oh, now we lost it. There we go, you’re back.

Dr. Ranak Trivedi: Okay, so good afternoon everybody. Thank you so much for taking the time out to hear about our work. I want to thank Molly for organizing this Cyberseminar. Today I’m going to share some work that we did as part of my career development award that ended earlier in the year, so in some ways this feels like a graduation talk. I want to start by thanking the team of people who have been involved in all of the studies that I’m going to talk about today, but most especially Dr. Piette who was my primary mentor on the career development award, as well as Karin Nelson, Chris Timko, Steve Asch, Steve Fihn, and then Dan Kivlahan, who were also mentors on my career development award. We had several funders for the various projects that I’m going to be talking about, and various partnerships we developed along the way. We’ll start with a poll question, just to kind of get a sense of the audience here.

Molly: Thank you. So for attendees, I am going to put up the first poll question. We would like to get an idea of what is your primary role in VA? We understand that you may have many different, you may wear many different hats within VA, but we’d like to get an idea what your primary role is. So the answer options are: student, intern, or resident; research; VA operations; clinical provider. And if you do not see your title here, at the end of the presentation I will put up a feedback survey with a more extensive list of titles, and you might find yours there to select. Alright, it looks like we’ve already had over 70% response rate, and I see a pretty clear trend, so I’m going to close this out and share those results. Looks like: 2% of our respondents selected student, intern, or resident; 49% research; 6% VA operations; and 43% clinical provider. Ranak, did you want to say anything about that, or should I move on to the next?

Dr. Ranak Trivedi: Yeah, thank you. Yeah, the next one would be helpful. So it seems like most of our people are here to understand the research or the clinical side of our work.

Molly: Excellent. So for our attendees, you have the second poll question up on your screen now. What is your interest in this topic: research; policy or operations; case management including caregiving; or clinical care? And it looks like the responses are still coming in. We’ll give people a little more time. I’m sorry, case management includes caregiver coordinator. Sorry I misspoke there. Okay, we’re going to go ahead and close this out and share those results: 42% of our respondents selected research; 5% policy or operations; 31% case management; and 23% clinical care. So once, again, thank you to our respondents, and I will turn it back to you one last time, Dr. Trivedi.

Dr. Ranak Trivedi: Okay, thank you. And thanks to everybody for, you can see my screen, right?

Molly: No, you’re going to have to press your My Screen one more time. It, the pop-up might be hiding behind, you might have to escape. There we go.

Dr. Ranak Trivedi: Okay, so it’s great to see for the variety of people who are interested in this topic, because one of the things we understand about caregiving is it’s going to affect us one way or the other. And especially as we think about American adults with chronic illnesses. About 80% of adults have chronic illnesses, and these include things like heart failure, diabetes, and depression, and a slew of other conditions. About 68% of these folks have at least two chronic illnesses, so there is a lot of things that people are managing at home. And managing these illnesses accounts for three-quarters of the U.S. health care costs. Most chronic illnesses require some kind of self-management recommendation, and these are activities that patients are asked do at home outside of their health care setting to optimize their outcomes. Common ones include manage medications, often there is dietary restrictions, there might be some physical activity recommendations. It also includes things like preventative care, like getting a flu shot annually, and then monitoring your symptoms and seeking timely care if they start feeling like their health is deteriorating.

There’s a lot of research, especially in dementia, that suggests that having a family caregiver results in better adherence to medications, and also to lifestyle recommendations like diet and exercise. There’s various mechanisms through which this might occur. For example, if caregivers are living with the patient, they might be able to kind of keep an eye on their patient. And they also often share activities. For example, if you live in the same household, you might prepare the same meal for the family, and you might be eating meals together. So you have kind of a, you can keep a closer tab on the various recommendations. Also when your family caregiver’s involved, there’s better care coordination with the team, and there’s a recent meta-analysis that also showed that having a caregiver present at the time of a hospital discharge improves both 60 and 180-day outcomes. And then there’s also emotional support that caregivers can provide so that their patients feel, have better emotional well-being. They may not get as depressed, or if they do, they’re better able to kind of seek help.

So what do we mean when we say family caregivers? Other terms that people have used are informal caregivers or carers, or care partners. So basically, an estimated 50 million Americans are caregivers across the board. The vast majority of caregivers are women, and about 40% are significant others. But of course, it’s worth recognizing that if two-thirds are women, that means one-third are men, which means that caregiving is truly a issue that affects everybody. If we were to start paying our family or informal caregivers, it would cost our country $470 billion dollars, and these are analyses that were conducted by AARP. So you can see that this is a huge service that our family and social network are providing to patients that is not getting as recognized as it ought to. And as I just mentioned, they can provide a variety of levels of assistance. There could be emotional support, it could be practical support. For example, often a caregiver might pick up medications, or pick up the mail, go get groceries. But increasingly family caregivers are being asked to do really complex medical tasks, which not too long ago was being taken care of by doctors and nurses. For example, wound care or dressing changes, or taking care of really sophisticated medical devices.

So because of all of these issues, caregivers can often feel burnt-out, and this concept is called caregiver burden, which is the strain that caregivers might experience, specific to their roles as a caregiver of a chronically ill patient. This burden could be because they have to juggle multiple priorities, they’re managing a resource, low-resource environment, they see their loved ones’ health decline, and then patients themselves may also not be able to take care of themselves. But that is not the full experience. Caregivers also experience the positive feelings that come from taking care of a loved one; the affection, the sort of satisfaction they feel in helping somebody in need. And these, there’s this kind of full spectrum of experience has only recently gotten a lot more attention. Another aspect that is getting some focus now is this idea that how did the relationship between patients and their caregiver influence their well-being. So how does that improve their interpersonal communication or the relationship quality influence how patients and caregivers work together towards a common goal. And this becomes increasingly important because we are getting better at, patients are living longer with chronic conditions, and we have become more focused on keeping patients in their home setting, which is part of patient-centered care. But that means we have to take a closer look at the safety net of the scaffolding, which is the family caregiver network that is helping us do so.

And so you can see that for the dyad, self-management is a joint-venture and it can be difficult, but most of the research has focused on patient barriers. So we know from looking at this patient that lack of knowledge, poor communication, even low education or socioeconomic status can play a role in patients having a harder time managing their health. But barriers experienced by family caregivers may also be important if you start thinking of family networks. How does caregiver burden play a role? What is the social support that caregivers themselves might need? And how can providers interact better with families so that they can do a better job of helping the patient take care of their health. And very few studies are simultaneously focused on barriers as perceived by all of these stakeholders, which is patients, the caregivers, and also the providers.

So there’s many unanswered questions regarding what we called the sociobehavioral mechanisms that underlie caregiving. For example, how do patients and caregivers collaborate and communicate around self-management? How does relationship quality influence caregiver involvement? What barriers do they experience together or separately as they navigate the health care system? And we need to understand these issues because only when we have a better understanding how these dynamics play out can we design intervention and strategies that can enhance patient outcomes, but without putting undue strain on the caregivers.

So last year we published this model that we are calling the Dyadic Health Behavior Change Model. And this model draws on existing conceptual models. The Leventhal Self-Regulatory Model, which is a common model that is used in self-management research. Also, Ventura Self-Efficacy Model. We also were looking for a model that can help us understand the interpersonal factors, and we focused on the dyadic coping model that was developed by G. Bodenmann in Switzerland. And his model specifically focuses on the relationship strain that is experienced by patients and their partners as they navigate a chronic illness. So we put these models together and our goal in putting these models together was to really understand how can we effect truly dyadic changes. How do we design truly dyadic interventions that factors in their individual outcomes, as well as the interdependence within a dyad?

So today I'm going to share with you three studies. We’re going to have, the first two studies focus on barriers and facilitators experienced by patient-caregiver dyads in heart failure self-management, and one of the studies also looks at provider barriers. The third study is with patients with depression, but takes on the task of interviewing two kinds of caregivers; caregivers who live with the patient, and those who live outside of their homes, to really try to get a sense of what are those dynamics and the communication, and other factors that play into managing these illnesses. Each of these three studies were mixed-method, and I’ll go into the specifics next.

The first study we presented at SBM last year, and we have a manuscript under review. This starts unpacking this orange box of relationship, because we were interested in the barriers and facilitators of heart failure self-management. Heart failure is a really important, growing public health concern. It’s the number one discharge diagnosis among Veterans, and it’s an illness that is, for which self-management is critical to both reduce the exacerbations of hospitalization, as well as extend life. But the self-management recommendations are really complex, involving multiple medications, close monitoring of symptoms, dietary restrictions, physical activity recommendation, and it has a deteriorating life course, which means that a patient may be less able to participate as the illness becomes more severe. So our idea was to understand what are the barriers and facilitators of self-management as it is perceived by patients, their spousal caregivers, and clinical providers. And spousal caregivers is a term used in the caregiving research, but it really means any significant other; it does not require you to be married.

We recruited all of our participants from the Palo Alto VA. A patient had at least one heart-failure related visit in the previous year, and they were required to have a caregiver who is a cohabitating significant other. We tried to keep our eligibility criteria broad, and we, as long as they were cognitively able to participate, they did not have a paid caregiver, for example a home health nurse, and were not actively on hemodialysis or receiving cancer treatment, we deemed them eligible.

We conducted semi-structured interviews with 17 patient-caregiver dyads. And our interviews with the dyads focused on: the roles they played during, in the various self-management activities in heart-failure; what are the barriers they experienced; and what is the motivation that they had to keep participating in self-management. The interviews were either in-person or over the phone; we gave them the option. Most of the interviews took place together, so both of them participate at the same time, but then we also followed this up with one-on-one interviews with each, either first the patient and then the caregiver, kind of serially. And the reason we did that is we’re following a methodology described in the literature, because we wanted to really get as a dynamic between the two, which is why we wanted to interview them jointly, but then we also wanted to recognize that sometimes people hesitate to share some things that might be private or they might feel like might hurt the other person’s feelings. So we wanted to make sure we captured those pieces, too. We also interviewed 13 providers from the Palo Alto VA health care system. We kind of sent out a broad call, and our eventual sample was 3 cardiologists, 3 internists, 5 nurse practitioners, 1 nurse, and 1 social worker. And these interviews also were in-person or over the phone, and we left it up to them to choose which one. And we were interested in understanding their perception in where the gaps in self-management occurred, what role they thought families played, and what were the, in their minds, barriers to managing heart-failure.

We transcribed the interviews using a professional transcription service, and then we analyzed the transcript using the thematic analyses methods that are described by Braun and Clark. The transcripts were independently coded by two coders, and then conflicts were resolved through consensus. All analysis took place using Atlas.ti software.

All the participants, the providers, the patients, and the couple, and the significant others, so those familial caregivers, pointed to a lack of knowledge was the key barrier to self-management. But they sort of had slightly different takes on it. The providers felt that there was a lack of appropriate and standardized educational materials. They felt that education was very important, and they felt that the information they wanted the patients to have was not getting through. One of our providers also talked about that, for example, a heart-failure diet is very important, but they noted that sometimes these recommendations are provided by the physician, sometimes by the nurses, and sometimes by the dieticians. And having a standardized way of giving this information might be better. Patients and the significant others kind of had the suggestion of having classes or groups that could teach them how to manage heart-failure at home. So here’s a quotation from one of our caregivers, saying, “It’s hard for me to say he’s having a heart attack or it isn’t. I don’t know. He was just very uncomfortable. He had pain, but I cannot say that he was deadly ill and I wish I could have a little bit clearer signs of, you know, what’s happening and what do I do now?” So caregivers are feeling that they’re being asked to monitor their patient, but they don’t feel they have the right tools to do so.

Already a theme that we’re seeing from our interviews was this idea of communication, and this was a big theme that was pervasive. Again, providers, patients, and significant others all talked about communication being important. The providers reported that communication gap, primarily with about their care plan. And for example, one provider said, “The nurse may be calling them on the phone and we might tell them to bring in their meds. But they are unclear on what…They’ll say the white pill over the phone, or bring it in, and then they’re matched, and they’re still trying to figure it out. It’s very confusing.”

On the other hand, patients felt, patients focused less on the actual communication in terms of the specific content, but more about the support they felt. So here’s a patient who’s saying, “I told my doctor that I’ve had trouble with my breathing. She didn’t understand what I was trying to tell her, you know? I just kind of got frustrated with her, but I didn’t say anything. I just said yeah, yeah, okay.”

So patients are kind of bringing up concerns, but they’re not feeling like the providers are really hearing what their concerns are. And then significant others, their main issues with communication was, they felt they had a really hard time communicating with the health care team, even though it was listed in the chart that they can call. And this was especially true for partners who are not married. But even if the people were married, they still felt that there was a barrier to receiving the important information that they needed to take care of their patient. And if patients attended clinical visits on their own, they felt that they, the significant others felt that they had to rely on the patient to give them the right information.

Yet, they also talked about having a strong, affectionate relationship that as something that really enhanced self-management, and having stress hampered it. So one of the nurses said we like having families involved. We do embrace the family member to take part and be strong with them. And a lot of our providers really supported the role of family, and wanted to see family involvement, and recognized that having better social support for the overall good for the patients. And then patients also noted the same thing. They said, “Well, I think whoever you’re going to help, they need the cooperation of both parties.” And what they mean by both parties is the patient and the caregiver. And then caregivers also said, “That’s why I think more wives should be involved in their husband’s health care as far as even going into an appointment, just to make sure that everybody knows what’s happening with the person.” So caregivers really wanted to be more involved with the self-management process, and felt that they, the closer they felt with the patient, the better they felt they could manage the illness at home.

So building on this first study with heart-failure, we also wanted to try to diversify the kind of dyad we were examining. In the second study, we were interested in determining the family characteristics that would help us enhance personalized patient care. One of our collaborators, a student who just graduated, Juliah Kim, used this work for her master’s thesis, that I’m going to talk about today. And we’re currently preparing a manuscript, as well.

So the goal with this was similar to the first study, but we were really interested in how they engage, not just with each other, but also the medical community around managing their health and illness. So this study starts to unpack this purple box on self-management. And the reason we wanted to do this just because we recognize patients on different dyads are more than just couples. All kinds of family members or friends may be involved. And yet, when we think about the dyadic interactions, most of them come from couples’ research. But if you can think of your own lives, you know that you might be providing support to friends or in-laws, or you see people providing care to their children, even adult children. And there’s research showing that different relationships have different experiences. For example, married or significant others, couples or significant others may experience more strain from helping self-management, but also experience more positive satisfaction and a positive uplift. On the other hand, the non-spousal caregivers experienced fewer strains, but also fewer, endorsed less satisfaction. The other piece that might be different is that a lot of these non-spousal caregivers live separately, which means they may play different roles with significant others in terms of how much they’re involved and how much they can monitor patients’ health. And they also have a different connection with the providers.

So for this study, we also recruited 17 dyads, as it turned out. That was a coincidence. And we recruited them from Stanford Heart Failure clinic. And in this study, we defined caregiver as anyone who was identified by the patient as being an important contributor for managing heart-failure. So it could be a partner, it could be anybody. We also conducted, again, semi-structured interviews with the dyad together, and then separately, just like we did in the first study, and our interviews focused on the daily challenges they might experience managing heart-failure, the various roles they would play, and how they communicated with each other, and the health care team. Again, our interviews were in 30 minutes to one hour. Most of our interviews were in-person. And then we followed-up with the one-on-one interview.

So some of the themes that emerged from this study mapped on to the first study, but there was also some differences. For example, one of our themes was that the health beliefs of patient and caregiver shaped their experience, whether [unintelligible 24:15] that they had to deal with, or they felt like they could kind of reconcile to it. So here’s a quotation. One of the patients said “you got to figure out you’re going to die sometime. You got to learn how to accept things in life”. And then another, and they often talked about a concept of resilience, and said, “We just live through it. We don’t let it hinder us from doing things. I bounce back and they can’t believe that I’m sick. So that’s been our thing; keep going.” And by our, they mean the patient and the caregiver together.

We also noticed that most patients and their caregiver experienced the positive and the negative feelings of heart-failure. They, the caregivers often talked about optimism and satisfaction of life and gratitude, as did the patients. But here’s a quotation from one of our caregivers. “Because you have two paths to go down, you have to pick which one, and so I choose to be uplifting and optimistic.” But then they also talk about the negative emotions; the stress, the depression, the caregiver burden, which is something that is talked about widely in the caregiver literature, but predominantly around dementia. And one of the caregivers said, “It’s a very big deal and scary that you got a defibrillator, so obviously there’s a lot of sadness and anger and frustration that I had because I wasn’t in control over any of this. It took a long time, years, to accept that this is what it is.”

And then finally, even though in this particular study we did not seek out to talk about the relationship, it was a very salient theme that emerged; that their quality of their relationship was an important factor in how well they got along, and how well they felt like they were managing their illness, and experiencing their end of quality of life. So one of our caregivers said, “I didn’t want to nag him anymore. I was just tired of nagging him. I realized that I was wasting more time instead of enjoying the time I had. I think what helped is remembering how much I loved him.” But beyond love and the gratitude and empathy, some people also felt like they were helping because it was their responsibility. And there’s less on this topic, actually, then in the literature, so one of our caregivers said, “Because I’m the oldest, I feel it’s my job. It’s our job to take care of him because he took care of us.” And this was, the father is the patient here.

So these previous two studies noted that both patients and caregivers experience the stress of managing heart-failure, and that providers, patients, and caregivers all experienced some of the same barriers to successful heart-failure management. We also recognize that caregivers may be motivated by a lot of different things, including love and empathy, but also it’s just responsibility. So we speculated that enhancing caregiver involvement may benefit patients as well as caregivers. Whereas providers may benefit from learning how do they effectively engage family caregivers, since they seem interested.

The third study was not focused on heart-failure. It was actually focused on depression. And depression, as everybody knows, is a very common condition, and it’s often comorbid with other chronic illnesses like heart-failure and diabetes. But we know that depression is inherently a barrier to self-management because patients with depression often lack the motivation or the energy to actually participate in their own care. So here’s a group of people who could really benefit from some extra support possibly, and we wanted to explore this population, as well.

This work that I’m going to talk about was presented by our team just a few months ago at SBM. And in this case, we wanted to understand the characteristic of communication, collaboration and relationship quality that underlie the interactions in three groups of people; the depressed patients, an in-home caregiver, and an out-of-home caregiver who we called the CarePartner.

So again, we’re trying to unpack this orange box here, which feels more of a black box in the literature and we’re trying to shed light on this. And the way that this study was set up was that we got supplemental funding from NIH to carry out the study. That was ally to an existing RO1, and the RO1 was a clinical trial looking at an automated self-management tool called Interactive Voice Response. And with patients and their care partners were randomized to either be in the intervention arm or usual care. CarePartners, again, were identified by patients as somebody who was a family member or friend, who lived apart from them, so not in the same house, and is somebody who has been or is willing to be, take an active role in the self-management of depression. And we conducted, again, semi-structured interviews. And each, these interviews were conducted individually with each of the three groups, and they were all over the phone because the parent studies based in Michigan, we’re based out of Palo Alto. And we talked about care coordination, communication, and relationship challenges. And a lot of our methodologies are similar to the previous two, so we’re not going to go into details on that.

All-in-all, we talked with 39 people, of which 18 were patients, 14 were care partners, and 7 were in-home caregivers. Most of our participants were women, but nearly almost 100% of over 90% of our CarePartners were women. This is a slightly younger population than our heart-failure population, with about 50 years old. It was predominantly white. Again, geographically, that is to be expected. And the last row is the PHQ, which is the depression measure. And patients who were kind of on the borderline of feeling depressed, and the CarePartners and in-home caregivers did not endure significant depressive symptoms.

Kind of carrying-on from the first two studies, the thing that really stood out for us in this particular study was the importance of relationships. All of our themes had some flavor of this, and we tried to dig deeper to kind of come up with something more nuanced, because there were so many ways in which people talked about relationships. First, they felt like relationship closeness was important for communication around depression. So here’s a quotation from an in-home caregiver: “We can talk about this stuff anywhere from a few minutes to a few hours. And usually we always end-up gaining insight on things. We kind of like bouncing ideas off of each other, personal growth stuff…we always feel pretty good after our talks…and just already having a good relationship foundation has helped I think.”

They also, patients also felt that having a support person improved their understanding of depression. So once again, having somebody involved helped them feel that they understood their own depression better. So one of the patients said, “Because she’s knowledgeable and she has a good handle on what depression is all about, where my husband and his family have never really had to deal with that, it’s a little bit harder for him to understand.” So she’s basically talking about in a CarePartner, who’s also a woman, who lives outside of the home, and she says, “And I just don’t open up to people about that kind of stuff, so she was the person that was, I felt, close enough and knowledgeable enough to help me work through it because she’s already done it before we started the program.”

And one of the things that was also really fascinating for us is that one way in which this intervention seemed to work for people was that it made their role of a caregiver exclusive to that was their role. And this is something that kept coming up over and over, and was somewhat of an unintended consequence of this study, of the kind of larger intervention study. So here’s a representative quotation: “Before the program, we knew there were issues, and you try and say something but you have to be careful because you did not want to offend or step on toes, or you didn’t want to over-assert yourself. But once he said that, yeah, he wanted some help with it, and I was kind of like, okay, you said you want some help with it, so we’re going to help you with it. Then you didn’t have to feel bad about saying something.” So people have sort of would notice that their patients were not, their friends or family member, were not feeling great, but didn’t know whether they were allowed to talk about it, and especially this is true for depression, I would imagine, more than heart-failure, because of the sort of stigma still associated with depression and this idea that you don’t want to pry into something that might be private.

So the first study for us really highlighted this idea that relationship closeness was critical to self-management; it influenced both perception of their own depression, the communication, and their knowledge. And then the CarePartner program, so this program that was designed to really help care partners help patients, really provided a platform to have conversations that people had wanted to have, but weren’t sure that they could. And although this was not a quantitative study, one of the things that we noticed in our, as we were doing our analyses, is that people who said that they had a close relationship with their care partner or in-home caregiver, also often talk about how much they felt they benefitted from the intervention. But not so much patients who did not feel like they had a close relationship.

So across these three studies, one of the things, the thing that really stands out is, regardless of what illness people might be dealing with, patients do manage their chronic illnesses imbedded in the complex social relationship. The other piece is the providers do experience barriers that are very similar to experience by families and patients, so it’s possible that having a health care system that is caregiver-friendly, and this is a term that I just learned from Courtney Van Houtven. A caregiver-friendly health care system might be really important to contemplate and think about so that we can truly treat patients within the context that they operate.

An emerging theme across this study, and something that doesn’t get enough attention is that the relationship closeness was important for effective communication, not just within the dyad, but also between patients and their health care providers, and then caregivers and their health care providers. So it’s possible that intervention that enhances closeness may improvement illness outcomes. And yet, one of the things that we find is that most self-management programs serve only the needs of patients. They are often illness-specific and often they talk about patients and how they might be undergoing the stress, and what they need to do, but barely take into account the roles of families, or the role, or the burden it’s facing. And at best, often programs might allow family caregivers to participate, or “encourage,” but the intervention is definitely designed for patient outcomes, and not really dyadic outcomes.

So we then set out to design one such study, which we’ve highlighted and published last year, which was *A Couples’ Based Self-Management Program for Heart Failure.* The remainder of the time, I’ll talk about some of our pilot data that’s also been published, so you can look it up or you can just drop me an email. So goals for this was to develop and pilot a truly dyadic self-management program for patients and caregivers that we have called SUCCEED.

And what we wanted to do was really target the purple box of self-management, but do so in a way that also targets this, the orange relationship box, as well as the blue boxes that are the individual factors that have an important role in self-management.

We wanted to develop a program that was feasible and scalable right at the very outset, we wanted to be very conscious of that, so we didn’t want to reinvent the wheel. There’s a lot of excellent programs out there, and we wanted to really build on that rather than try to build something denotable. So we used a conceptual model that the dyadic health behavior change model, and expert’s input to identify three programs that we felt had some of the components that we wanted to really use. The Chronic Disease Self-Management Program that was developed right here at Stanford by Dr. Kate Lorig and her group, the VA National Caregiver Training Program, which was developed by Meg Kabat and the Office of Caregiver Support, and the Couples Coping Enhancement Training Program, which I eluded to earlier, which was developed by G. Bodenmann of Switzerland based on his dyadic coping model. Each of these programs had components that we felt were critical in improving dyadic outcomes, but we felt that none of these programs really stood alone in doing that. So we felt that we wanted to come up with something that built on these specific pieces in them. We then used stakeholder input from patients and caregivers, both through our qualitative work, as well as by presenting our work to the Palo Alto Veteran and Family Council. We took their feedback to heart, and I’ll talk about it in just a minute. Then we also involved education experts and we iteratively developed and defined it based on feedback as we went through the program.

So our first step was to identify the key intervention targets, which we identified through a conceptual model, as well as when we did our first qualitative study, which was of patients, caregivers, and providers, and understanding what are the places that people really want an intervention that they have not received. We then developed SUCCEED by identifying key components of our three parent programs. And then we went to the Veteran and Family Council, which is in, Palo Alto has a stakeholder group that meets monthly, and we presented our work to this council, and really took the feedback to heart. They helped us make sure that our program was short enough and feasible enough that they felt like it was right for the audience. They also suggested that we deliver it over the phone, or at least provide it as an option. And we used that feedback to successfully complete the pilot. We also involved our local education experts, and if people haven’t done this before, I highly recommend it because one of the biases that we bring as researchers is that we tend to use really complex language sometimes because that’s happen how we are communicating to the scientific community. But the education experts really made sure that the concepts that we were trying to communicate were communicated clearly and effectively to the right audience so it didn’t feel as though we, were, so we could get our message across. And then we, of course, pilot tested it.

So this is the program we pilot tested. We call it SUCCEED, which stands for Self-Management Using Caregivers’ Coping EnhancEment in Disease. It was 6 sessions that were delivered in-person or over the telephone. And because it was a pilot study, we just let the patients and caregivers pick how they wanted to do it. They also had the option to do a combination, but as it turns out, most people just wanted to do it over the phone. The program was delivered weekly in 45 to 60-minute sessions. It was delivered by Masters’ level facilitator. Initially it was our project coordinator, Cindy Sidem, and then later there was a facilitator, Erin Daltons, who we also trained. And our 6 sessions focused on, sort of, an overview in managing heart-failure, skills to manage negative emotions, and skills to manage interpersonal relationships and relationship stress, and then finally building a fulfilling life and maintaining behavior change. After each session, they completed a homework, which was an action plan, and then we reviewed the homework and any barriers they encountered at the next session.

Our feasibility was recruitment and retention, as it is for a pilot study, and we also received participate feedback on a 5-item Likert scale. And rating was anonymous and was sent to us on a rolling basis, but we collated it. We kind of kept the envelopes sealed until we had a critical mass so we did not, we didn’t unwittingly unblind the ratings. And then people did a slew of studies, because they also wanted to understand whether people would, how many surveys are too many.

Oh, and see the top box of this appeared. We sent the invitation to join the study to a bunch of people that we’d identified through registries and clinics. I apologize for the top box being missing. I just noticed that. But eventually we had 70 people who enrolled in our study. Three people withdrew before starting session one because of worsening of patient’s health. And nine completed all six sessions, and five completed fewer than six.

As with other pilots, what you would expect with other pilots, we iteratively refined the recruitment strategies. For example, we were initially required by IRB to use opt-in letters, which means that patients had to contact us if they wanted to hear more, but after having frankly dismal recruitment with this strategy, we convinced the IRB to at least allow us to have opt-out, meaning that if we did not hear from them, we could still contact them to see if they wanted to participate in the study. Through the study, we also wound up editing our invitation letter, and then we trained an additional facilitator, which helped free-up our DART project coordinator’s time to focus on recruitment. This allowed us to change our initial recruitment from less than 4% to 5.4%, and although 5.4% looks low, it’s actually comparable to other heart-failure studies, and it’s actually really, it’s about comparable to another dyadic study in heart-failure, so we felt pretty good about our final recruitment strategy. Our changes also improved our rate of improvement. So it took us six months to recruit seven couples, initially. And then the next ten couples, it took us less than three months.

People rated the sessions very highly. I have created the, one of the axes, I’ve created the y-axis so that it’s, we amplify the differences rather than the similarities because most people rated each session very highly. The session that was rated the highest was the last one, which was building a fulfilling life, but the overview session was generally rated pretty low. So we wound up, one of the refinements we’re now making is that we dropped the first session, and just have a five-session program now.

We also had people fill out surveys, and people’s heart-failure specific quality of life increased a little bit, but their general quality of life seemed to deteriorate, which we speculated might be because of, sort of, as time goes on, people get sicker. I forgot to mention, it took, even though we were planning a weekly session, it took an average of 11 weeks for people to go through the program, so it’s more like every two weeks is when we were able to get people to participate. So it took about three months, rather than a month-and-a-half. The signal that really stood out for us, that got us really excited was this self-care of heart-failure index, with the caveat that it’s very few people. This is an index that has been widely tested, and it predicts outcomes for, including hospitalization and mortality. And scores over 70 are considered in the adequate range, and changes of about five are considered, is about half a standard deviation. So we thought that overall, people’s maintenance, management, and confidence increased across the program, which, with the caveat that it’s very few people, was an encouraging signal for us.

So to summarize this, the first study, we successfully were able to develop a dyadic self-management program based on a strong theoretical foundation, and that was refined based on feedback from multiple content experts; patients, providers, and other key stakeholders. Of course, the limitation is that with, like, all pilot studies, it’s a small study, so of course we need to get efficacy data before we can make any conclusions about whether it works or not. This pilot study has implications for improving self-management. It allowed us to refine the recruitment process. It also allowed us to understand the personnel that were necessary to conduct an RCT. And then have encouraging results regarding acceptability and feasibility.

So what’s next for us? We have submitted an RO1 that is under review right now to test the efficacy of our SUCCEED program. In carryover, we’re also adapting our SUCCEED to be delivered as a self-education piece to be completed over the web. And we got an HSR&D pilot grant to do this, and a couple other small grants, locally. We also want to continue observational studies to continue to understand what are the sociobehavioral and the biobehavioral mechanisms within the patient and caregivers conflicts that determine self-management, as well as other well-being outcomes. Another place that we are going to continue to explore is understanding cultural and ethnic differences in caregiving. A lot of the caregiver literature is based on the majority culture; the measure which is racially light, and also nuclear families. And in caregiving, especially, the concept of family could vary so differently across cultures, whether it’s racial/ethnic boundaries or other types of non-traditional families. So we’re exploring studies that would allow us to kind of compare, for example, individual versus collective cultures, multigenerational families, and family units that identify with LGBTQ. So collectively, our program and research has really dug deep into the mechanisms that underlie the caregiver involvement. And our goal in doing this is to continue shedding light on the important aspects of caregiving, not just to recognize how important they are, but really in what way can we better engage them and tailor our interventions so that we can continue to provide more real world care to our patients and recognize the roles that their families are playing and how they might be embedded, and how those forces outside of our clinics can be an important contributor to their own well-being and other health outcomes.

So with that, please feel free to contact me if you, here’s my email address. That’s my phone number, although there’s an extension, and I think it’s 25225. And I’m happy to take any questions.

Molly: Excellent. Thank you so very much. So for the attendees that joined us after the top of the hour, to submit your question or comment, please use the questions section of the go to webinar control panel located at the bottom of the control panel. Just click the arrow next to the word questions. That will expand the dialogue box. You can then type your question or comment in, and we will get to it in the order that it is received. So first off, we just have some comments that have come in. Thank you for this excellent presentation. This is very helpful. Will these slides be available after the session? Actually they are available right now. You can either write-in to the questions section for the link, or you can refer back to the reminder email you received this morning, and there’s also a live hyperlink in there. And for the first question: Have you observed that caregivers also have chronic conditions that they’re managing?

Dr. Ranak Trivedi: Yes, and one of the reasons why, so I didn’t get into, sort of, lot of the weeds with our sample characteristics in the interest of time, but especially with the couples with heart-failure, that is to be expected. Our, in our first study, while our heart-failure patients reported about seven other chronic conditions, our caregivers also reported three chronic conditions. And as our caregivers age, we can definitely expect this to grow. And one of the many reasons why the dyadic self-management programs can be really influential for a lot of couples, there’s not really a clear distinction between who the patient is and who the caregiver is for that very reason. I think a lot of the information we provide to “patients” is actually applicable to the full families for the managing of their own condition, not just the person that is kind of the person who’s our patient who we’re interested in.

Molly: Thank you. For the next question we have: Regarding intervention possibilities based off study three, what are your thoughts on ways to enhance relationship closeness? My clinical experience is that patients often want this, but don’t know how to go about achieving it.

Dr. Ranak Trivedi: So our program, the SUCCEED program, gets into that a little bit. So our modules, the fourth and fifth, or now what’s going to be third and fourth modules, actually focus specifically on how do you improve communication and collaboration, how do you improve intimacy, especially if you’re partnered with each other, and trying to leverage the positive aspects of the relationship that might already exist and amplify it, and not just pathologize the couple or the dyad of somebody who needs help, but really sort of amplify the positive, and address both the negative aspects, and just recognize that there are interpersonal, there’s interpersonal strain that can occur, even if your relationship is otherwise really strong. Because people do feel push-and-pull when they’re trying to help another person manage chronic conditions. So you’re absolutely right. And in their third study, which is the depression study, that I think what you’re referring to, it could be very different. So our pilot study that we just got, that we’re doing the web-base, we’re developing the web-based program, we’re actually going to pilot it with heart-failure patients, the diabetes patients, and depression patients so that we can actually understand how it might be a different, we might need to think about it a little bit differently for depression because of the varying disease, might influence how they might see relationship closeness and intimacy.

Molly: Thank you for that reply. Many people writing in looking for the slides; they’d like to share them with colleagues. Once again, you can either write in for the link, or they are in the reminder email, or you will receive a follow-up email. And it looks like no further pending questions at this time, but I’m sure. Well, there it is. Can you talk about the pre-and-post-intervention results on the NCS and TCS? Scores went down, but higher is better, correct?

Dr. Ranak Trivedi: Yes, and we kind of, we’re all scratching our heads a little bit with that because it’s something, with 17 couples, there’s only so much you can make in front of one or the other, but obviously it’s disappointing when you see anything going in the wrong direction. We speculated, there’s two things that kind of stood out. One is because it took about three months, on an average, to get through, the people’s health would have deteriorated. So it’s possible that just played a role into it. The other piece of it is the data I presented were both completers and non-completers, and a lot of people, people who did not complete these six sessions didn’t complete because their health deteriorated. So we, it’s possible that again, the deterioration of the patients’ health was so influential in their quality of life that that could play a role. It’s the pre/post that’s hard for us. It’s possible that we did something to lower their quality of life, but we did feedback interviews for people who even, who decided to not complete the study, we did feedback exit interviews with everybody, and generally the feeling, we didn’t really get any negative comments or anything that suggested that our program had kind of, had added a burden, but obviously it’s still possible and it’s something we’re going to monitor it closely when we do bigger studies, because we would definitely want to make sure that we’re not doing that. The other surprising piece of that is that it’s actually generally pretty hard to change general quality of life, which is why it’s not such a great primary outcome for intervention studies. So we would expect for it to stay roughly the same, even if it didn’t improve, so it was surprising and something we, you know, we don’t, we just speculated, but, you know, in larger studies, we’ll continue adding that measure and monitor whether people are feeling worse, especially compared to control groups.

Molly: Thank you for that reply. The next question: I will be leading a caregiver chronic illness support group, and am interested in resources you might share on the intervention. Is the intervention available?

Dr. Ranak Trivedi: Well, it’s not tested, so you know, I’m happy to share some of the resources that we gave out, and definitely feel free to backchannel me, and we can talk what kind of resources you are looking for. I’m weary of sharing the intervention, per se, but we can talk what is its use because as something that’s not been tested and shown to work, kind of, independently, we want to be circumspect about using it as though it is something that could be helpful. But I’m happy to have a separate email and phone conversation about that. So definitely reach out to me, but yay, support group.

Molly: Excellent. Can the, she says sounds great, and I will reach out. And the next question: Can the intervention be used with patients who also have mild cognitive impairment?

Dr. Ranak Trivedi: We don’t know, but we want to find that out actually. So it’s a really good question, and something that we’ve talked about. We haven’t tested it. If somebody’s interested in doing that study, I’m happy for us to talk and collaborate on that. I’m personally very curious how the interpersonal dynamics play out when it’s mild cognitive impairment. So I don’t know the answer, so if you’re seeking to find that answer and want to lead a study, I’m happy to partner with you.

Molly: Excellent. Will there be a larger study to include other VA’s in the future?

Dr. Ranak Trivedi: I’d hope so, because funding. There, that’s our goal. So with our, the RO1 that we put in would do that. So the RO1 will do Palo Alto VA and Stanford, but certainly because of the numbers needed, we would be looking to expand to other sites. So yes, it would be great to do a multi-site study for the breadth. We continue looking for ways that we can do this kind of work, but, you know, as you, funding is always an issue. So we’re planning on it. It’s a question of when we’ll do it.

Molly: Excellent. Thank you. That is the final pending question at this time. I would like to give you the opportunity to make any concluding comments, so feel free.

Dr. Ranak Trivedi: Yes, thank you for spending the time hearing about the work. The CDA mechanism is an amazing mechanism and it gives you a lot of opportunity to learn a lot of different things in a protected way, so I definitely feel very privileged that I was able to share my CDA work with you. I also will put in a plug. I also lead the National Caregiver Research Interest Group, so if you’re interested in this area of research and you are not part of our group, definitely email me, and we can add you to the group. We do about monthly calls, and we do works-in-progress, we are planning to do some methods talks. So the more people that are part of that and are willing to share their work, I think the more vibrant our community can be.

Molly: Thank you. Well, I’d like to thank you very much for coming on and lending your expertise to the field, and thank you to our attendees for joining us. A special thanks to Barb Elspas and the entire CDA Enhancement Initiative Group for organizing these monthly Cyberseminars. And for our attendees, I am going to close out the meeting in just a second, so please wait while a feedback survey populates on your screen, and take just a moment to answer those few questions. We do look closely at your responses, and it helps us to improve presentations, as well as the program as a whole. So once again, thank you, Ranak, and have a great rest of the day everybody.

Dr. Ranak Trivedi: Thank you so much. Bye, bye.

[ END OF AUDIO ]