Cyberseminar Transcript

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Series: Spotlight on Mental Health

Session: Whole Health from the Perspective of VA Caregivers: Findings from a Photovoice Study

Presenter: David Meyer, Esq., MBA, CISSP; Gala True, PhD; Sharon Urbina

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Molly: And with that, we are at the top of the hour now so I would like to introduce our speakers. Presenting for us today, we have Dr. Gala True. She’s core investigator at South Central Mental Illness Research, Education, and Clinical Center in Southeast Louisiana Veterans Health Care System. Also a research associate professor at Tulane University School of Medicine. Joining her today, we are grateful to have Sharon Urbina. She’s a primary caregiver and spouse of an OIF Marine Corps Veteran. Joining her is David Meyer, Esquire. He’s primary care provider and spouse of an OEF/OIF Marine Corp Veteran and an attorney and cyber security expert in the New Orleans area. Sorry for botching that a little bit, David. And with that, we are ready to begin. Dr. True, are you ready to share your screen?

Dr. Gala True: Yes.

Molly: We should have that pop up now.

Dr. Gala True: Okay. Great, we’re good, Molly?

Molly: Looks great, thank you.

Dr. Gala True: Ok, great. Hello, everybody, and thanks so much for joining us this afternoon. My name is Gala True and I’m here on a beautiful afternoon in New Orleans with my research partner, Sharon Urbina and David Meyer.

Molly: I’m so sorry to interrupt. Can you actually go up into the slide show mode? Just one more icon to the right.

Dr. Gala True: One more icon to the right. Woops, yep.

Molly: Move over the screen a little?

Dr. Gala True: Oh, got it. I need my cyber, my cyber security expert just showed me how to do it. I’m here with Sharon and David. Sharon and David, do you want to say a quick hello?

Sharon Urbina: Hello, thank you for having us today.

David Meyer: Hello. Very happy to be here.

Dr. Gala True: Thanks. So in our presentation today, I’m going to start by framing the context for our research collaboration, then Sharon will share her experiences and perspectives followed by David, and then I’ll come back to make some final remarks and we’ll have some time to take your comments and questions. The presentation today is part of a series highlighting collaboration between VA Mental Health Centers of Excellence, including the MIRECCs, and the VA Health Services Research. So we’d like to thank the organizers of this series for giving us the opportunity to present today and also to Molly Kessner and her colleagues at CIDER for making these Cyberseminars possible. The work discussed today is supported in part by the South Central MIRECC whose mission is to promote equity and engagement access and quality of mental health care for Veterans facing barriers to care, especially those living in rural areas. Funding for this study came through a three-year HSR&D award entitled Communicating Impact of TBI on Community Re-integration through Photovoice.

So we’d like to start off with a poll question by asking you a little bit about your level of familiarity with Photovoice. So I’m going to turn it over to Molly for a minute.

Molly: Thank you so much. So for your attendees, as you can see on your screen, we do have the first poll question up. So once again, we’d like get your, get an idea of your familiarity with Photovoice methods. So are you very familiar, somewhat familiar, or not familiar at all? Looks like we’ve got a nice responsive audience. Already 75% have voted, so thank you for that. And I see a pretty clear trend, so I’m going to go ahead and close this out and share those results. Looks like 75% of our respondents say they are very familiar, 21% somewhat familiar, and 66% not familiar at all. So thank you to those respondents, and we’ll turn it back to you now.

Dr. Gala True: Okay. Great. Thank you so much. So it’s really helpful to know that. We are going to talk a little about our methods today. We won’t have time to go into great detail about Photovoice, but we do provide some resources at the end of our slides so that you can learn more about Photovoice if you’re interested. And you can always email me and ask me for more articles about Photovoice as well if you want.

So Photovoice is part of a continuum of community engaged research. The goal of this approach includes greater involvement of research partners in shaping research questions and deciding what to document and what stories to tell about themselves and their communities. Photovoice involves giving cameras to participant collaborators and asking them to document their daily lives, their challenges, their unmet needs, and resources around a specific issue or health condition.

Through discussion of the photographs and their meaning and what participants want others to learn through their photos, there is immediate co-construction of knowledge with Photovoice. Photovoice diverges from many traditional research methods in its focus on shared ownership of study findings and decision making about dissemination of findings, and that’s part of what brings Sharon and David and I together today. Photovoice typically includes a dissemination phase focused on educating others about research findings in non-traditional formats and venues, building capacity for future collaborations between the individuals who participated in the research, others in their community, and the researchers who led the research with them and then advocating for changes to policies and practices that effect the individuals and communities who participated in the research.

So the work we’ll present today grew out of another Photovoice project funded through a VA HSR&D pilot funding, which we ended up calling “From War to Home.” You can learn more about that project through our website, which is listed at the bottom of this slide and at the end of our presentation. With From War to Home, we worked together with Veterans, and they tell us that the act of taking photos and talking about their photos helped them reflect upon difficult and sensitive topics such as moral injury, traumatic brain injury, and post-traumatic stress. Together we create a photo exhibit using Veterans’ photo narratives that has been travelling continuously for five years, and we’ve given a series of presentations over the past five years where Veterans have used their photos to share their perspective. And they talked about how they found the photo narrative approach really helped them share their stories in ways that felt both safe and meaningful.

With that project, one of the things that happened was that the caregivers and family members of Veteran participants became involved in the project very informally and I got to know them very well. They would come to the different presentations and Photovoice exhibits and panel discussions, and they kept saying to me over and over again this is wonderful, we love this project gala, it's been really meaningful, but you should be getting our stories as well because that’s really part of the story of the Veterans that were, who are our family members.

So that’s part of how this project actually grew, the current project that we’re going to be talking about, some of the Veterans who were involved in that first project, in From War to Home, and their caregivers were involved in development of the study we’ll be drawing from today. So we really followed that participatory action research kind of model where they helped me think about what would the next research phase look like? What kinds of questions should we be asking and what kinds of methods should we be using? Some Veterans from the original project serve on the advisory board for the current study and others continue to help disseminate findings and advise on the research.

So this brings us to the current study which focuses on caregivers as well as Veterans. One of the things that we learned in working with Veterans in the first Photovoice project was about the importance of understanding their experience and perspectives. So there are currently over one million people who provide informal caregiving to post 9/11 Veterans. There was a large 2014 RAND report that we provide a link to at the end of this talk that was a large survey of caregivers, both military and civilian caregivers, and looking at caregivers pre and post 9/11 Veterans. And some of the findings of that study were that the caregivers of post 9/11 Veterans are much more likely to be younger, they’re more likely to be the spouse of the Veteran or partner, and they’re more likely to be working at least part time outside the home in addition to their caregiving duties. So they have a lot that they’re carrying with them. They’re also less likely than civilian caregivers or caregivers of Veterans of other service eras to have a support network, and they’re about two times as likely to be providing care for a Veteran who suffers from one of the invisible wounds of war such as TBI or a behavioral health condition.

We also know from this report and from our experiences working with caregivers and being caregivers that despite the many rewards of caregiving, many military caregivers also experience significant health problems as well as strains in family relationships, including those with the Veteran in their lives, and also extended family and friends and also negative impact on their work trajectory, their careers, and other activities that they can take part in outside the home.

So that brings us to the focus of the current study where we wanted to collaborate with OEF/OIF/OND Veterans who had a TBI and their caregivers, and we define the caregiver as the person with the Veteran identified as most closely involved in supporting them in their daily lives. So using Photovoice methods, we gave them cameras and asked them to share their experiences with health care and community reintegration. And we also asked them to engage with us in identifying target areas and strategies to improve post deployment care and reintegration for themselves and their larger community.

So I wanted to acknowledge all of our collaborators on this project. We’ve been working together for the past few years diligently, and I really want to especially acknowledge Dr. Sarah Ono, who is my co-investigator and the site PI at our second site in Portland, Oregon, and also Mary Frances Ritchie, who is the program coordinator there, as well as our team in New Orleans, which includes a number of very dedicated people including Ray Facundo, who is a Veteran who collaborated on the original From War To Home project. We also have a very involved and supportive steering committee, which includes equal numbers of Veterans, caregivers, and VA representatives. And we also definitely want to acknowledge the other care partners or caregivers and Veteran collaborators who worked on this project with us. They’re not here with us today, but they’re here with us in spirit.

I’m going to talk very briefly about what we call the participants' journey through collaborating on this project. I’m going to try and use my cursor for this. So first we slightly modified traditional Photovoice methods in order to work with Veteran and caregiver pairs. First we met individually with participants to go over informed consent, conduct research ethics training and Photovoice training, talk about what the goals of this project would be, and give them the cameras. We met wherever was most comfortable and convenient for participants, which usually was in their homes. So we have that great opportunity to get to know them a little bit, to get to know people a little bit in their homes and spend time with them there. We asked them to take photographs and contribute photographs from their personal collections to tell their stories. And then we went back and met with each person individually in order to talk about their photos and the meaning behind each photo and talked to them a little bit about their permissions in using the photos. So any photo [audio hiccup 12:08] people had given permission for those to be used in this project.

We then went back to our office and created an individual photo narrative for each participant and mailed that out to them and checked in with them about whether there was anything they wanted to change about that or whether they thought it accurately represented their experiences and views.

We then asked them to share their photo narratives with their study partners. We asked Veterans and caregivers to share those photo narratives with each other. Then we went back and met with people again but this time in a dyadic interview to do an interview with each Veteran and caregiver pair and ask them about their experiences of participating in the project and sharing their photo narratives with each other. And finally, we had a series of small group meetings where we’re beginning to identify priorities for dissemination of findings in areas where findings can be used to improve care and experiences of Veterans and caregivers which led us to dissemination activities such as today’s presentation.

So today our focus is on our caregiver participants, and this is just to tell you a little bit about their background. Of the 26 caregivers who are collaborating on the project, most are the spouse or partners of a Veteran, nine are enrolled in the VA family caregiver program, a little more than half have children, and most are women and under 40 years of age.

So where does this focus on whole health come from that we’re going to start to talk about today? Well, it emerged in our group meetings where participants said they wanted to disseminate findings to healthcare providers and policy makers to make sure they understood what was important to caregivers and Veterans in terms of how they thought about health and quality of life, both for the Veteran and for themselves.

Our steering committee members in one of our steering committee meetings brought up the importance of the Whole Health Initiative within VA and really the importance of understanding what whole health looks like from the caregiver’s point of view. We also attended and did some presentations together at our local annual mental health summit where we had a panel on integrative approaches to mental health recovery. We talked about what community resources exist to support whole health and where our facility stands in terms of implementation of the Whole Health Initiative. And finally, some of us attended a local caregiver appreciation event organized by our facilities caregiver support program where we had the chance to talk with other caregivers about where they find support and what their end met needs are and learned a lot from them about what they consider to be a whole health approach.

So I’m only going to talk pretty briefly about the whole health approach at this point. But again, we provide links to more information in the slide at the end of the presentation if you’re interested in learning more. Briefly, the whole health approach is a big initiative in the VA that's being undertaken by the VA Office of Patient Centered Care and Cultural Transformation. We’re working with VA leadership and healthcare providers to transform VA’s health system from the traditional medical model, which focuses on treating specific medical issues, to a personalized proactive patient-driven model that promotes whole health for Veterans and their families. So the shorthand way of talking about this is saying instead of asking patients what’s the matter with you, ask them what matters to you. And you can see here the circle of health, which puts some emphasis on the Veteran, the patient in the middle, but surrounded by all of these different aspects of whole health including family, friends, coworkers, which is where caregivers would fall into the circle. And they're surrounded by thinking about preventative health, complementary and conventional approaches to health, and then fully surrounded by the communities that patients live in.

This is a screenshot of the Whole Health Library. If you want to learn more about it, we’ve got a link at the end of the presentation. But basically the emphasis is on creating healing environments, healing relationship, and practice of whole health that places each person at the center of his or her own healthcare and shifts the focus of care towards health and well-being.

And finally, there’s a really extensive Veteran resource page that highlights some of the resources that are starting to be deployed within VA that help patients and families be able to think about things like healthy eating and nutrition, the importance of sleep and sleep hygiene, mindfulness, and approaches to improving the health environment of individuals and communities. So in terms of the implementation of the Whole Health Initiative, the Office of Patient Centered Care and Cultural Transformation conceptualizes the implementation of falling along three possible phases. The foundational stage where plans are being developed and preparations are made for implementing aspects of Whole Health approach, the enhancement or sort of intermediate stage which builds on outcomes of experiences of early stages of implementation to further enhance change, and the enhancement or advanced stage which builds on outcome and experiences, I’m sorry, and the cutting edge stage where the organization can serve as an expert resource and leader for others who are implementing whole health.

So I wanted to take a minute and ask you to reflect for a minute on where your facility is in terms of whole health implementation, and so we’re going to do one more poll before I hand it over to Sharon and David. So Molly…

Molly: Thank you. So attendees, as you can see on your screen, we do have the second poll question up there. So as Dr. True was saying, we would like to get an idea of where your facility is at in terms of whole health implementation. Would you say they are at the foundational or early stages of implementation, at the enhancement or intermediate stage, at the " cutting edge" or advanced stage of implementation, or you do not know/does not apply. And people are a little slower to respond to this one, and that’s fine. Take your time and give it some thought. Okay, we’re right up to around 75%response rate. So I’m going to go ahead and close this out and share these results. It looks like we have 26% of our respondents saying that their facility is at the foundational or early stage of implementation, 16% reported at the enhancement or intermediate stage, 7% said at the cutting edge or advanced stage, and half of our respondents do not know or it does not apply. Thank you once again, and I will turn it back to you now.

Dr. Gala True: Okay, great. Thank you. That is helpful. I mean I think one of the things that we wanted to do today was really kind of come in at the early stage of implementation of the whole health to engage the question from the caregiver's perspective about what does whole health look like from the caregiver's perspective because the emphasis has been largely on the Veterans, which is as it should be, but we’ve been thinking and talking about how can caregivers who walk alongside their Veteran in the quest for health and well-being, what can these caregivers tell us about Whole Health? What are their points of view on what needs to happen within VA to reach whole health goals as we kind of start with this transformation? And what are already existing VA and community resources that can be harnessed to move us closer to realizing the goals of whole health? So with that framing, I’m going to turn it over to Sharon to share her experiences and perspective.

Sharon Urbina: Good afternoon. My name is Sharon Urbina, and it’s a pleasure to be here with you guys today to share some of my experiences as a caregiver and some of my photos from Photovoice. My husband, Carlos, is a combat Veteran who served 16 years in the Marine Corp, and he currently suffers from severe PTSD and TBI. My journey as a caregiver started unknowingly when he got back from his second tour of Iraq, but I just became his full-time caregiver about two and a half years ago when he became unable to manage his symptoms. He has completed two inpatient programs, one of them being with the VA, and two outpatient programs and continues to work on his overall wellness every day. I would like to share some of the alternative therapies that he uses to achieve this wellness. What whole health means to us, to me and my husband, is to be able to integrate alternative therapies and community resources so that Carlo can achieve the highest level of independence that he possibly can. We have been successful using VA resources and community resources that are tailored to more of his specific needs.

Here’s a picture of Carlos participating in a Veteran program where the Veterans utilize equestrian therapy to improve their wellness. It’s a private institution called New Heights that allows Veterans to connect and ground themselves through working with horses. This has been extremely beneficial for Carlos because he’s able to practice his coping skills and to build relationships with other Veterans that he works with. He started just volunteering with the Veteran group and now also works with children. He has a lot of pride to give back to his community in this way, and he has felt that he had lost that when he got out of service. He looks forward to volunteering with them and it actually gives him more back than the time that he actually is there.

This is a picture of Carlos playing his guitar. He was introduced to the guitar through a program through the VA offers. It’s called guitar for Veterans where he was able to attend classes like guitar lessons with other Veterans. Through the program, he was able to build confidence that he could learn new skills and ground himself in the moment. One of the obstacles that we have come across is the difference in VA resources and services through the different regions. This program was offered at the Denver VA but is not offered at the Louisiana VA. And one of the opportunities that I see is for consistency across regions so that all Veterans have access to the same resources, and this will also help Veterans as they transition getting out and from one region to another region.

One of the main ways that Carlos reduces stress and helps manage medication side effects and is able to build positive self-esteem is through exercise. We’re lucky enough to have a gym around the corner from our home so that he can access this resource for his overall wellness. It took a long time for us to understand the direct correlation of exercise to Carlos’s wellness and how serious it was. In one of the inpatient programs, he was offered yoga classes that he had never done before, and when he started it, he really found so much benefit from it. So we are fortunate that we understood early on that this was a resource. Exercise and having access to a place to exercise was beneficial for him. But that’s not the case for all Veterans. And I believe that we need to work harder to make sure that Veterans have access or the availability to resources that fit their own needs, whether it be fishing or mountain climbing or a book club or meditation.

This is a picture of us actually using the Veteran Choice Program. I found the Veteran Choice Program to be very beneficial for Carlos, and we’ve been able to meet his care needs in a timely manner. What I’ve found is that some providers are more comfortable using the Choice Program than others, and some specialties won’t consider using it at all. I manage all of Carlos’s medication, which can be very difficult when outside providers have different medication management programs, don’t prescribe medication that the VA covers, or the community provider is so far away from a VA pharmacy that the prescription can’t be filled in a timely manor. I’m also concerned that his medical records won’t be transferred back correctly or in their whole entirety and that this could cause a break in care for him or unnecessary overlap in service for him.

I’d like to conclude with these pictures of me and Carlos. I call them our happy pictures because it goes to show that using a whole wellness approach and community resources, we’ve been able to come so far. We were able to participate in a friend’s wedding and were able to go out on date nights again, which were things we wouldn’t be able to do two years ago, and that he can actively participate by using the skills that he has learned to be able to enjoy these activities to their fullest. And that, to us, is what really matters. So I would just like to thank you for having me here today, and I’ll turn it over to David.

David Meyer: Thank you, Sharon. My comments will mirror Sharon’s a whole bunch. And I just want to start out by saying that for those who are unfamiliar with Photovoice, the program is very intimate because it is very revealing, and as a result, it is a safe space to share. And from a caregiver perspective, I was unaware of the amount of sharing that I needed to do when I first met with our group and when I first met with Gala and Ray. And that, in the words of a famous philosopher, has made all the difference.

I’m going to begin my comments on my photographs by saying that I agree with what Sharon mentioned. To me, whole health must include an understanding of the intricacies of navigation within the VA healthcare system. The voluminous amounts of health-related information, for instance, you see here my husband’s disability application. It’s over 1,200 pages. The amount of information should not be an excuse to have intended care goals go unmet. For instance, Sharon mentioned the community-based Choice Program providers. Our own experience with the Choice Program has been very positive where it is available to be used. Some internal [unintelligible 27:53] in the VA can cause unintended consequences when a simple network code is changed, for instance. So such intricacies should be aware, or should be made aware when thinking about the Veteran’s whole health. Next slide, please.

That is my husband. He is an eight-year Marine Corp Veteran. That picture, like Sharon’s picture, we were talking before the presentation. We both had photographs of the medication management issue. My comment on this slide include the fact that a whole health strategy must include the active participation of a Veteran’s caregiver, especially because poly-pharmacy issues can arise. Inclusion of the caregiver, whether it be the spouse or whomever is the caregiver, helps to assure positive outcomes because there is someone else advocating for the caregiver. VA clinicians and providers should not purposefully or even unintentionally cause the caregiver to experience what they perceive that’s either actual or perceived exclusion from any aspect of the Veteran’s care. The caregiver knows more about the Veteran’s issues from a comprehensive perspective, I will authoritatively say, better than the VA. If you want to ask any question, you can review all of the text files and all of the notes that you want, but just ask their caregiver because we know, we have the answer.

As an aside, we have experience to nothing but inclusiveness at our New Orleans VA Medical Center, which is doing a good job of encouraging the active involvement of the caregiver during the Veteran’s care program. This is my third and final photograph. This photograph represents my husband’s nest. We call it a nest because everything is within arm’s reach, whereas some Veteran problems are, can be either mostly mental or mostly physical, and of course a whole spectrum of everything in between, my husband’s key problem is physical. He does have mental problems as well, but that’s idiosyncratic to any Veteran. My husband has chronic fatigue syndrome, which means that he cannot physically perform many activities of daily living. And so when he is not in a position physically to go to the medical center, there can be particular aspects of his care that may be overlooked.

Another point that I want to bring up, and this will be the last point that I want to make, is that different branches of the armed forces have different learned behaviors that are instilled at the initiation of training. And an idea that Dr. True communicated to me that I had not previously considered is the idea of military cultural competency by VA clinicians. For example, a Veteran who served in the Marine Corp who went Paris Island or to San Diego, it doesn’t matter,they’re both relatively the same, although I’m sure some will disagree with me on that statement. A Veteran who served in the Marine Corp is more likely to actively withhold certain health-related information, especially mental health-related information, simply because Marines are trained to suppress emotions and are trained actively to not seek medical care during boot camp. Such learned behaviors can hamper the Veterans seeking treatment after service is completed. So therefore, awareness of such differences between the military branches can be the key to delivering positive outcomes. And I also want to say thank you for listening, and I will now turn it over back to Dr. True.

Dr. Gala True: Thank you so much, David and Sharon. I really appreciate it. And we’ll have time to have more discussion and questions and comments from the audience as we wrap things up.

So I just wanted to come back on for a minute and kind of give a wrap-up of some of those things that David and Sharon and I and the rest of the team have learned from working together with some of the other caregivers and their narratives on the project and talking about these things. So one thing is that we want to be able to engage a little bit with this circle that is sort of at the center of the Whole Health Initiative, and we all think it’s a wonderful circle and we had a lot of time talking about it. But there are a few points that we wanted to make about where do caregivers see themselves in this circle. And we realized that that really depends on the caregiver and the Veteran and the situation, so we’re not trying to make too broad a stroke about it.

But we did have some points we wanted to make about things like, that caregivers such as David and Sharon really feel like they need to be all seeing and aware in all situations and have continual awareness. So when you look at all of the kind of circles that surround the Veteran here, caregivers see themselves as kind of floating around and needing to see all these different things and think about, you know, is the Veteran exercising, as Sharon said. You know, what are their surroundings like? As David talked about, David has talked to me about needing to get special equipment into the home to make sure that Donny can shower and bathe and things like that and engage in activities of daily living. The caregiver needs to be thinking about food and drink and how does the Veteran recharge and all these different aspects.

So these caregivers really see themselves as strategic partners in the Whole Health Initiative. We also recognize that there can be an ebb and flow in terms of that relationship, so caregiver involvement may evolve over time and may be different at different times depending on the Veteran’s needs and desires. But caregivers, overall, are really motivated, as Sharon said, I think to help their Veteran reach his or her full potential as a person.

Caregivers also, as David has pointed out, are constantly having to try and balance their resources, so they spend quite a bit of time and energy on navigating different systems of care, VA, DoD, and the Choice Program. And when they spend, you know, David shared with us one day that he had spent, I think, about four to six hours on the phone during a work day trying to navigate the Choice system.

David Meyer: Choic Program.

Dr. Gala True: And all that time and energy that’s being spent on that is not going towards other ways of supporting the Veteran. It’s really going towards just navigating bureaucracies and systems and that can be very draining.

And then the final point around this is that you’ve got the Veteran in the middle, you know, who is me as it should be, but a lot of caregivers point out that while the Veteran can be focused on me, the caregiver is almost always focused on us. So those are some of the points that came out.

Caregivers in our project also have, we’ve come up with some tips for providers, some really practical tips, things like just ask a Veteran do you have a caregiver or care partner when you start working with them. You can also think about using language such as someone in your life who is involved in supporting you in your health and well-being because not all younger Veterans or Veterans who see themselves being very self-sufficient or who need to feel like they don’t need to be taken care of or they don’t want to complain about their symptoms. They may not identify with the word caregiver, so you may need to use more broad language in order for them to identify someone.

If the Veteran says yes that they do have someone like that, you can simply ask, would you like to invite this person to participate in this or future visits or have me communicate with them in general. And then obviously need to set up where we recognize that there needs to be some setup around being able to have those communications or have someone in the room while there’s a visit going on.

If the Veteran says no, then the question might still be who is your support system? What do you do when you feel overwhelmed? We’ve talked quite a bit about our concern about the many Veterans who don’t have a caregiver. What happens to them? Who advocates for them when they get overwhelmed by navigating all these different systems or by trying to express what their symptoms are or access care?

If the Veteran does have a caregiver or care partner who is involved in their care and a provider is talking to that Veteran about medication or particular health issue or appointments or follow-up they need to do and the Veteran seems lost in any way, for example, continues to ask the same question over and over again, then the provider could be prompted to ask the Veteran something like would you like me to call your caregiver about this and talk to them about it as well in order to make sure that that information doesn’t get lost or overlooked.

One thing that really has come out of this project from caregivers is the overall importance of finding helpful people in the system who will realize when a caregiver is being passed around from person to person, not getting their questions answered, and nothing is being resolved, and finding that helpful person who will tell them, look, I’ll look into this and call you back. And then they actually do call back, that those kinds of people are very important resources.

So what are some opportunities and future directions for supporting caregivers and taking their viewpoints into account in whole health implementation for VA? One thing that really came out of a lot of our discussions was about the importance of utilizing community-based programs and support groups and VA support groups, but thinking also about tailoring those resources to the age and generation of the caregiver and the Veteran so that they’re appropriate. So for example, if the Veteran or caregiver are older, they may be dealing with different health issues than OEF/OIF/OND Veterans. And so what kind of resources are there in the community and within the VA to support those caregivers and those Veterans?

We’ve also talked quite a bit about the need for support groups for rural dwelling caregivers and maybe thinking about what are some virtual platforms for support for people who can’t always travel and make it to in-person meetings. As Sharon pointed out, we’ve talked about increasing the consistency of integrative health approaches across facilities and regions so that those are available to all Veterans in a more consistent manner. I think there’s also a lot of possibility for us to consider developing programs such as caregiver navigators who can help caregivers coordinate across these complicated VA and Choice Programs and take away some of that burden for them so that they can spend the energy supporting their Veteran in other ways.

And then obviously, we’re all very invested in thinking about how can we engage caregivers more consistently and carefully in thinking about VA research and program evaluation because they have so much to offer in terms of thinking about what kinds of questions do we need to be asking, how do evaluate programs as we implement them. And they can obviously comment on things that are geared towards caregivers but also on programs that are geared towards Veterans. Caregivers really need to be involved as well. And then another question which is kind of an overall, very big overarching question is that question of who [inaudible 40:17] so I have the privilege of spending time with Sharon and David and seeing everything that they do for their husbands. And I also am aware that they need people to care for them as well and support them.

So I wanted to leave you with this quote that we really like that we thought summed up the way that Sharon and David and other caregivers in the project and also many VA providers and community providers and community members around us are approaching and should be approaching recovery and wellness for Veterans and whole health. It’s never give up on someone with a mental illness, and you could replace mental illness with any kind of physical illness or anything like that. When "I" is replaced by "we," illness becomes wellness.

David Meyer: Great quote!

Dr. Gala True: So we have a list of some resources and sources that you can follow up on if you’re interested. We’d also like to acknowledge the funding for this project. And now we would like to open things up for your questions and comments.

Molly: Wonderful. Well, thank you each very much. We do have some questions and comments pending. For those of you that joined us after the top of the hour, please submit your question and comment. For a comment, please use the GoToWebinar control panel located on the right-hand side of your screen. Just click the arrow next to the word question. That will expand the dialogue box and you can then submit your question or comment there. If it is for a particular presenter, whether it be Dr. Gala True or Sharon or David, please specify that in the beginning or I will address the group with it.

The first comment came in from a Veteran during Sharon’s portion talking about going to the gym with her husband. For other outlets in the community, if a Veteran is not able to make it to the gym, is Project Hero. It is a cycling non-profit organization that myself and other Veterans participate in, additional information for any Veteran seeking physical activities suffering from PTSD, TBI, or other physical disabilities. Thank you to our commenter. So, again, the name of that is Project Hero.

Dr. Gala True: That’s really helpful. Thank you, and we’re so excited that you’re listening to the talk today. We do, I know actually I should let Sharon say this, but we do all try to compile lists of resources and share them with each other. And I know, Sharon, you’ve put together like a list of resources.

Sharon Urbina: Yeah, as I have come across resources and I’ve spoken with other caregivers, you know, the conversation kind of goes what have you guys been doing? Well, I’ve been doing this, and then you, as you're in this conversation, you begin to grow a longer list of resources that you wouldn't know about. So that’s great. Thank you so much.

Molly: Thank you. We have lots of people writing in. They're saying thank you, everyone. So I’m going to have to give those as a general. There is a large consensus of thank you for sharing this. But in the essence of time, I'm going to lump those nicely together and continue on with the questions. The first one, how do you get Photovoice past your local VA R&D committee, ISO, privacy, etc.?

Dr. Gala True: Sure, that’s a great question. I mean I’m happy to be in touch with whoever that is. They can email me at Jennifer.True2@va.gov. So I did the first Photovoice project about probably six years ago, and it was incredibly hard to get certain aspects of it through the IRB and ISO, and I learned a lot lessons from that, that I’m happy to share. Maybe not go into in too much detail today, but I will say things like we pay very careful attention to partnering with participants so that they control the disclosure of information, how their information is used and shared. They decide if they want to do things, if they want to use their real names in the project. Obviously this being the VA we have to do a lot of tricky things in terms of protecting the data, the photographs, uploading them to a secure server. We use the VA photo and consent form so that participants can give blanket consent for us to use their photos and stories in education and dissemination of findings. But then we also have an additional consent form where people can really specify how they want their photos and stories used in the project, so they can say I want my full name used or I want to use a pseudonym. They can designate certain pictures to be anonymous or to be used with a pseudonym if they’re not comfortable having those particular pictures being used with their name. So we really go through a lot of very careful steps to think about how to partner with Veterans and caregivers rather than treating them as traditional research participants if that makes sense. But I’m happy to answer more questions about that in an email.

I don't know. Do you guys want to talk at all about your experiences with...

David Meyer: Oh yeah, this is David obviously. It was interesting to have complete control over all aspects of the Photovoice program. We were given the options, as Gala said, of yes, no, maybe, anything in between, and that was very comforting to know that our information was secure and that we had total decision control over all aspects of it.

Sharon Urbina: The Photovoice project for me was the first time anybody had ever asked me what my personal story, my personal journey looked like or felt like or that as I traveled the journey with my husband, and it was actually very healing to be able to express myself in a safe way. And I felt safe and I felt understood and I felt like my opinions mattered. And I always joked because I cried through my whole interview, but that’s because it was so meaningful that somebody really just asked me about me. And it’s been such a healing experience for me.

David Meyer: I’ll echo what Sharon just said as well, yes. Very much so.

[Crosstalk 47:10]

Molly: I know I said I'd lump together all the thank you messages, but there’s one in particular that I’m going to pull up here. As a transgender Veteran myself, it was wonderful to see a non-CIS hetero relationship documented in an official VA presentation. Thank you for that.

Dr. Gala True: Thank you.

David Meyer: Oh, yeah. Thank you for that comment, yes.

Molly: The next one, both Sharon and David chose pictures of many pill bottles. Does anyone help them review all the medications to ensure that they’re working well together rather that interacting to create new problems?

David Meyer: Yeah, I can comment on that directly. I have two comments. The first is that the VA pharmacy itself usually, or at least the one in New Orleans, has a Pharm-D. I’m not exactly sure off the top of my head what that designation stands for, but that person is very well versed and schooled in the interactions and dependencies on medication management. So if there are questions from the poly-pharmacy or from the pharmaceutical side, yes, there is someone at the VA to whom you can go directly with questions.

The second note is that as part of the overall Whole Health Initiative, having an outside app on your phone that can, like we use Epocrates. You input all of your medications and you hit go, and it will tell you very quickly and easily which medications should not ever, never, no, don’t ever take these together, or this is okay, but this is not, and so forth along the entire spectrums. There are definitely resources out there to consider on that topic.

Sharon Urbina: And as a caregiver, I carry a list, an updated, always working, moving list of medications with me at all times. And the list is also updated and kept in my husband’s wallet just in case of, in case of an emergency such as a car accident where I wouldn’t be with him. And usually the question to every prescribing physician that he has is did you review the previous medication list and just continuously asking are these medications ok to take together.

David Meyer: Great question.

Dr. Gala True: This is Gala. I’m just going to jump in one second, too, and talk about other caregivers in the project who found it very challenging to manage all these medications and I think in one of the earlier slides where I showed the participants, the demographics of the participants, just that many people pulled out journals for us and took pictures of them like books where they kept notes of all their Veteran’s medications. People took pictures of the ways that they organized and managed medications. There were a lot of photographs of multiple medications and poly-pharmacy to talk about those challenges. And not everyone is well-resourced and organized as David and Sharon, and so there are people in the project who really encounter challenges with getting medications refilled or not being told that the medication is out of stock. And if it doesn’t come in the mail, sometimes they don’t realize that for a week or two, so their Veteran would inadvertently be not taking the medication they were supposed to. So I mean David and Sharon definitely represent two extremely kind of organized people who have been doing this for a couple years. But there were many caregivers in the project who were quite overwhelmed by the poly-pharmacy, so I think that’s a great question.

Molly: Thank you. Could you talk about or share if anyone is doing work in this area adapting whole health for Veterans with cognitive loss and their caregivers?

David Meyer: I can address that. Cognitive dysfunction is a hallmark of chronic fatigue syndrome and TBI and PTSD for my husband. We were very fortunate to be routed at the New Orleans MHC, the mental health clinic, to the one person who could bring us into the family program at MHC. And because of that, we had a very quick integration into mental health from a family perspective to include me as a caregiver and not just the Veteran alone. And for that I will be eternally grateful. Not to name drop, but his name is Fred Sauder [phonetic], and he is an incredible person and just a very dedicated individual. I do want to say that getting into mental health and navigating that is obviously, as probably everyone on this phone call knows, is its own or could be its own presentation. But once in, we were able to access the resources we needed.

Sharon Urbina: [Unintelligible 52:38] add?

Dr. Gala True: Not, no.

Sharon Urbina: Okay.

Dr. Gala True: Thank you, David.

Sharon Urbina: Yeah.

Dr. Gala True: I mean I will say that, just to add a little bit, that one of the themes that has been coming out of this research that we could do a different presentation on is the challenges that Veterans and caregivers face to accessing services that are specifically for dealing with cognitive issues. I think a lot of people would say that they feel like maybe there’s a lot of services available for PTSD or there’s a lot of medication available or things like that, but that they might say that there’s not quite as much that they would like to see to help them with symptoms related to their cognitive issues. And that can be a source of great frustration to Veterans and caregivers.

Molly: Thank you. All right, I’ll continue on. We’ve got several pending questions. This is phenomenal work. I’m curious about whether your caregivers, including those on the line, have had providers ask them about how they are doing, whether they need more training or support, or about their preferences in their caregiving.

Sharon Urbina: I personally haven’t been asked by one of my husband’s providers how I’ve been doing or needs for myself. I am a participant in the VA caregiver program where I have a coordinator, and she definitely looks out for my best interests to make sure that I have the resources that I need to care for myself for the longevity of this journey that we’re on. But as far as has one of my husband’s providers asked me, I can say no, I haven’t been asked.

Molly: David?

David Meyer: I can echo that and respond in a tangential manner to say that although my husband’s VA providers do not always ask. Two things. One, I make it known assertively how I am doing, whether good or bad or anything in between. So I can break through. I use humor and my just general assertiveness to make my current condition known. But then the second part is, is that now that Sharon and I have met each other and we have a third group participant who is not on the line with us today, but she is getting into our group. But I digress. I just wanted to say that Sharon and I, or rather Sharon has been my rock and that I did not know that I, as a caregiver, needed somebody else to talk to who was familiar with the situations and the experiences that a caregiver goes through on a daily basis. And so once I found Sharon through the Photovoice initiative, again, as somebody famous once said, that has made all the difference.

Sharon Urbina: Thanks.

Molly: Thank you. How can providers integrate the caregivers more in the clinical visits?

Sharon Urbina: Something that the New Orleans VA has done is when they pull up my husband’s profile, I’m automatically, he is automatically flagged that he has a caregiver. And so I have found that very beneficial when I need to call and make an appointment or when I’m in appointments with him. I think that speaking to my husband and asking, directing let’s just say appointment to him, it’s important that he doesn’t feel devalued or talked to about in the third person. But when they notice that he is starting to struggle, to look to me to be able to help him through explaining what his needs are or to have me be able to explain them for him. Just the acknowledgement that I’m there as his full-time caregiver is actually, I believe, the most important thing is that they, the providers acknowledge that we’re there and that we are a big part of their care and we really just want what’s best for the Veteran.

David Meyer: As I said, thank you, Sharon. As I said earlier, if there is a question about any particular aspect of the Veteran’s care from a comprehensive standpoint, then ask the caregiver. We know the answer. If we don’t know immediately, we will damn sure find out quickly. Because we are living this every day in the caregiver role, we are exposed to, I would say, all aspects of care. And so a good way to improve caregiver participation is to, as Sharon said, acknowledge the caregiver’s role but also to engage the caregiver directly. Don’t discount the caregiver as merely being a body in the room. Ask the caregiver questions and engage the caregiver directly, and that can be very helpful.

Dr. Gala True: Great. I’ll add one really quick thing. So in the first Photovoice project, I’ll never forget there was a Marine in the project who took a picture of a binder full of paper. And he said to me, when he was getting out of the service that his sergeant major said to him you need to make what I call the I love me binder. And Sharon is nodding. So the I love me binder is like your DD-214 and all your forms and everything. So he had the I love me binder. So now that I’ve been doing this work with caregivers, I’ve seen what I would call the I love you binder which is what the caregivers make. And so I think the providers could simply ask a caregiver when they’re starting to work with a patient, do you an I love you binder or do have like something you want to show me a notebook. It doesn’t mean they have to look through the whole 2,000 pages or whatever that David has put together and hole punched and probably put ring binders on, whatever. But just asking about it and letting the caregiver maybe say, oh yeah, I have this notebook and this is where I keep track of all of this could be a very helpful way for the provider to begin to understand how the caregiver is organizing things and what they know.

Molly: Thank you. I still have a few pending questions, but we’ve reached the top of the hour. Are you three able to stay on and answer those so I can capture them in the recording?

David Meyer: Yes.

Dr. Gala True: Yes.

Sharon Urbina: Yes.

Molly: Excellent. For any attendees that have to drop off at the top of the hour, as you exit the session, please wait just a second while the feedback survey populates on your screen and take just a moment to fill out those few questions. We do look very closely at your responses. That helps us improve the program. So we’ll get through a couple of comments and then we’ll get to the last few questions.

Just as a comment, speech pathologists may be an under-utilized resource for cognitive therapy. Patients may not realize that speech therapists are trained to evaluate and treat many cognitive symptoms. Thank you to that respondent.

Dr. Gala True: That is a great, sorry, go ahead, David.

David Meyer: That’s a great point. That is actually not something that I had considered until just mentioned. Thank you for that.

Sharon Urbina: Yeah. My husband, he suffers from TBIs and he does utilize speech therapy through the VA and has done some extensive speech therapy through a private institution, and they did, they really, it was very beneficial to him. So thank you.

Dr. Gala True: Yeah, thank you very much. That’s a great, we have heard that from quite a few Veterans who’ve said that it is the speech pathologist who has really helped them, and so that’s something really important to consider. We appreciate that.

Molly: Thank you. Do you require both the Veteran and the caregiver to agree to participate in Photovoice? Can a caregiver participate even if the Veteran does not agree to?

Dr. Gala Truth: That’s a great question. So the way that this study was funded, we had to have a Veteran participate, and if they could identify a caregiver, then their caregiver could participate, would participate with them. So we actually do have some Veterans who participated solo in the project. We obviously didn’t really present their work today. But we did not have caregivers who participated without the Veteran. And that was, honestly, I mean I could have written the protocol to say that caregivers could participate without the Veteran, but it would’ve been difficult, it would’ve been a different study, I think. So it’s a great question. I think as hopefully as people are doing more caregiver research, they will include caregivers even if the Veteran doesn’t want to participate, but we did not do that with this study.

Molly: Thank you. How would a provider refer a patient for community-based services that aren’t usually covered by VA such as a gym membership near their home? What kinds of these services can be covered?

David Meyer: I’ll take that because I have direct recent experience with it. From what I understand, and pardon me if I’m using the incorrect vocabulary, but certain services can be or must be outsourced when not available at the VA medical center itself. The list, or rather the networks of providers fall, again, in my own experience, into two different categories. Both categories are based upon the recent legislation in the past three to four years.

The first category is the VCP network, which is the Veterans Choice Program network. Many providers chose to not participate in the VCP program for whatever reason. General fear about government interaction, paperwork, and any other BS you can think. The reason, I don’t know if I’m supposed to say that or not, but too late. But their reasons vary, but the end result is the same. The VCP program was the original program for Veteran’s Choice that everyone heard about a couple years ago.

The more recent one, however, is the PC3 network which is the, it’s an acronym that stands for Patient-Centered Community Based Care. And the nasty part of the dichotomy between the two programs is that many providers are in the original VCP, the Veterans Choice Program network, because they signed on when that first was created three years ago. However, in the more recent year, I believe, the PC3 network evolved or was legislated into existence, and the benefits for the PC3 network are different from and better than the original Choice program. So a lot of providers signed up for the PC3 network and did not sign up for Choice. However, the rub is that once a provider is in one network, the VA medical center may believe falsely that they’re in both and that is not necessarily the case.

That is a long answer to say that for many programs that, or rather specialties that are not necessarily covered by the local VA medical center, it takes a little bit extra work to verify and confirm that the provider is under the correct network when the referral is made.

Dr. Gala Truth: Wow, I can’t even...

David Meyer: And that was the at least six hours that I spent at my office working on this, so yeah, I have detailed notes.

[Crosstalk 1:05:00]

Dr. Gala True: Oh, go ahead.

Sharon Urbina: Oh, I’m sorry. I would just like to add, not to that, I don’t have experience in that world that David was just talking about, but there are organizations like the equestrian there be, that they are outside, they have outside financial benefactors that help put those programs on. And there other organizations that give discounts to Veterans. So even if it’s not a direct referral from the Choice Program, there are outside, Veteran friendly organizations that are trying to make those resources available if it doesn’t necessarily have to have a referral through, from a provider.

David Meyer: I’m going to jump back in and comment on what Sharon just said that in relation to it that when, to answer your question directly, how someone makes a referral to services outside of the VA is to go to either your PACT team leader, who can, if they're diligent can figure it out, or go to the specialty clinic where you have your provider and ask. For example, my husband gets acupuncture. It is the only thing that really benefits him. Yoga, meditation, Tai Chi did not help. Acupuncture does. And the day that I spend six hours on the phone dealing with the different networks, it was, the whole issue was that the network was changed and nobody knew that the only provider in the entire metropolitan New Orleans area that performed acupuncture was on one network but not the other. So start with your PACT team leader. If not your PACT team leader, go to your specialty clinic and just ask. More often than not, they will be happy to refer you out to someone when they cannot perform it in-house.

Dr. Gala True: Great, thank you. But I can, I mean I’m listening to this and I’m just picturing the need for navigators to help with all this. But thanks for that question.

Molly: Absolutely. Okay, I'm going to have to wrap up at 4:10, but we’ll go ahead and try and squeeze in these last two questions. For Sharon and David, do either of you work outside the home full time or part time?

Sharon Urbina: I worked outside the home until my husband became extremely, became acute, and I left my profession to take care of him full time.

David Meyer: I am lucky enough to have a job that is cognizant of my caregiving requirements and can adjust my work schedule as necessary. I work full time but can take off when I need to.

Molly: Thank you. The final question is for Gala. Will your Photovoice exhibit be touring anytime soon? I do believe there’s someone in Bedford, Mass., that would very much like to see it.

Dr. Gala True: I guess, I’m guessing, I mean the exhibit from this project, because the From War To Home exhibit, there's two copies. One copy is in Hawaii and the other copy is in Columbus, Ohio, and actually a few pieces are also up here in the New Orleans VA. And our hope definitely with this current project is to create a similar exhibit and have it tour, definitely. So anybody who wants to start planning, because it’s first come, first serve is the way we work.

Molly: Thank you. Well, that is the final question. However, I do want to give folks a chance to leave us with any final thoughts that you have. So I know you're all in the same room, so I’ll just let you look around at each other and hear you sum up.

Sharon Urbina: Do you want to go first? Some final thoughts, I guess, that I have is that I’m very proud to be a caregiver and to give the care that I give to my husband. It’s the most important job I have ever done. And I feel that other caregivers feel the same, and we take it seriously and are, I’m excited to see how the Whole Health Initiative can benefit my husband and other Veterans in our community.

David Meyer: So my final thought is, one more time, how grateful I am to Gala and team for putting me in contact with Sharon and for putting my husband and I in contact with Sharon and Carlos because they have been a great outlet when needed.

Dr. Gala True: I would like to say thank you to everyone for joining today and maybe staying on the line and also to Sharon and David for doing this presentation today. It’s very difficult, I think, to share your stories and your intimate stories and your marriage, really, your relationship with perfect strangers, and Ray and I started off as perfect strangers to them much as Sarah and Mary Frances did to the participants in the Portland area. And then for them to be willing to share that on a wider stage really shows a lot of dedication to not only their relationship and their Veteran but also they're really considering the other Veterans and caregivers out there and what can we be doing for them. So I want to thank them for being willing to do this. And hopefully someone in Hawaii will watch the exhibit and we’ll have funding to fly out there together [unintelligible 1:11:04] exhibit along with everyone else in the project.

Sharon Urbina: All right. Well, thank you.

David Meyer: Thank you, Molly, very much.

Dr. Gala True: Thank you.

Molly: Thank you all so much for coming on and lending your expertise. And to David and Sharon, thank you for your efforts and your advocacy. It is absolutely seen and appreciated by us all. And thank you to our attendees for joining us. At this point in time, I’m going to close out the meeting. [Unintelligible 1:11:28] please wait just a second while the feedback survey populates on your screen. We do look closely at your responses and it helps us improve the program and individual presentations. Thank you, Dr. True. Have a great day, everyone.

[ END OF AUDIO ]