

The Lewin Group
Involving and Supporting Family Caregivers in Care Planning and Delivery
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Caroline Loeser: My name is Caroline Loeser, and I am with The Lewin Group. Welcome to the webinar, *Involving and Supporting Family Caregivers in Care Planning and Delivery*. This is the fourth webinar in the 2017 Geriatric-Competent Care Webinar Series.

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Today's session will include a 60-minute presenter-led discussion, followed up with 30 minutes for a discussion among the presenters and participants. This session will be recorded, and a video replay and a copy of today's slides will also be available at <https://www.resourcesforintegratedcare.com>.

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This webinar is supported through the Medicare-Medicaid Coordination Office at the Centers for Medicare and Medicaid Services. MMCO is developing technical assistance and actionable tools based on successful innovations in care models, such as this webinar series. To learn more about current efforts and resources please visit our website or follow us on Twitter for more details. Our Twitter handle is @Integrate_Care.

At this time I would like to introduce our moderator. Carol Regan is a Senior Advisor for Community Catalyst's Center for Consumer Engagement and Health Innovation and has over 30 years of experience with national and state-based public policy and advocacy organizations. Carol?

Carol Regan: Thank you, Caroline. Welcome, I am delighted to again moderate one of our many Geriatric-Competent Care Webinars.

Community Catalyst and our Center is an organization that is committed to working on bringing the consumer voice into healthcare decisions that affect their lives. Over the past few years, we have been delighted to work with The Lewin Group and the Medicare-Medicaid Coordination Office to put forth policies and practices that improve the care for older adults. We are committed to working on that, and this is one of the ways we are able to push out education and good models, so we are delighted to have this webinar.

I am going to quickly introduce our incredible faculty. I'll introduce them in order.

Dr. Anita Major studied medicine at Baylor College of Medicine in Houston, Texas. After an internal medicine residency in Manhattan at Cornell's New York Hospital, she completed a three-year geriatric fellowship in Miami at Jackson Memorial Hospital and the Miami VA. She returned to Houston in 2010 to serve as the Director of the Geriatric House Call Program at the Baylor College of Medicine.

She's a clinical educator and has experience in interprofessional education. Her clinical practice consists entirely of supporting homebound, frail elders. Dr. Major finds empowering caregivers as one of the most gratifying aspects of her career. At personal level, she cares for her mother-in-law at home, who suffers from a traumatic brain injury, and she spends time with her husband, who is a retina specialist. She also has three young children. So we welcome Dr. Major.

Allison Dobecka is a Nurse Practitioner and has been employed by Baylor College of Medicine in Houston with the Geriatric House Calls team since August of 2014. She worked with a private company in the same capacity in Dallas a year before joining Baylor, and prior to this she was a Registered Nurse at St. Luke's in Houston for seven-and-a-half years.

Allison earned her Masters of Nursing in adult primary care from the Texas Women's University in Houston after earning her bachelor's degree in San Antonio, Texas. Allison teaches geriatric medicine focused on in-home care to medical students, residents, fellows, as well as nurse practitioner students.

Then we have Tziona Regev. She's a Licensed Clinical Social Worker specialized in gerontology, and she's got extensive experience in geriatric clinical care, over 30 years, in program development, interdisciplinary collaboration, case management, consultation and education. Tziona delivered and championed services primarily for older adults and other age groups with physical and mental disabilities.

The last speaker we have is Hattie Coleman. Hattie is a family caregiver herself. She left her job about six years ago to care for her mother. Hattie will talk about her personal experience and share that with us.

We have a great group to speak today, and we're really looking forward to hearing from all of them.

Now, let me turn it over to Dr. Anita Major, who will start off our presentation. Thank you.

Anita Major: Thank you, Carol. As we face the demographic changes that are occurring in this country, it's increasingly important to recognize that our aging population will obviously require help. In fact, 80 percent of elderly Americans requiring long-term care currently live at home or in the community, and unpaid family caregivers provide 90 percent of their care.

When we think about government expenditures, \$66 billion were spent on Medicare and health in 2015. Compare that to the incredible \$375 billion that caregivers saved the government in spending.

Recently the term "sandwich generation" has been coined. This refers to caregivers who are sandwiched between the needs of their children and those of their aging parents. I am part of this group, as are the majority of caregivers. Balancing these competing interests of dependent family members complicates caregiving further.

How do we identify caregivers? They are not always relatives. They do not always live near the care recipient. Sometimes they are paid, but often not. Sometimes they themselves are elderly and suffer from disabilities. Regardless, we endeavor to educate, empower and assist caregivers in all that they are tasked with.

They will strive to meet the financial, emotional, social, functional and medical needs of their elders. The image of a superhero coming to the rescue sums all that caregivers take on.

Here is where the superhero analogy really makes sense. The mnemonic is DECAF.

D - Caregivers can be asked to assist with direct care provision, which might include bathing, dressing and toileting, which are activities of daily living, or cooking, doing the laundry, managing medications, and even medical therapy, such as nebulizers or tube feeds. These tasks are physically challenging.

Next is E, the emotional support that elders require as they come to terms with their own decline in function, their own loss of independence, or even social isolation or depression.

C stands for care coordination, which is not only navigating the healthcare system but also determining how and when to transport care recipients to those services that have been arranged.

A is for advocacy, which is a crucial task that caregivers undertake. Elders that require caregivers are by definition vulnerable and often cannot communicate their concerns or preferences.

Last but not least is F, the financial commitment that caregivers make to ensure all necessary medications, equipment and supplies are available to the care recipients.

One of the first lessons I learned in geriatrics is to get another perspective when taking a history. Initially I would speak to the patient directly upon meeting him or her in the emergency room, but then I would always try to involve a family member or friend to either corroborate what I had already heard or add to my understanding of the situation. The same principle applies with care planning.

As with all things in medicine, before we make an intervention we first have to make a diagnosis. I apologize for how clinical this sounds, but I utilize this concept on a daily basis. When I teach medical students, for example, my initial step is to find out what they already know so that I can best tailor my educational efforts and maximize learning.

An important term commonly being used in the caregiving literature is "dyad." This refers to the combination of the care recipient and the caregiver and conceptually links them as one entity.

A critical first step in assessing the dyad is identifying what they understand about their situation. What do they know about their chronic medical conditions? Do they have realistic goals and expectations? Do they know what to expect as the diseases progress?

Knowing the context of the dyad is also important. Who makes up the family unit? What is the financial status of the dyad? What has the duration of caregiving already been before you actually get to meet them? Clarifying goals of care and how the dyad wants to be helped is essential in guiding care planning.

Lastly, there is meaning in every relationship. What was the nature of the relationship between those in the dyad before now and how has that changed over time? Diagnosing the dyad should be a systematic process of gathering information to identify the specific problems, needs, strengths and resources of the caregiver, as well as the ability of the caregiver to meet the needs of the care recipient.

In medical education we utilize the SPIKES protocol as a framework for delivering bad news. I find it useful in caregiver assessments as well.

First, the setting should be optimized, and ideally this means separating the caregiver from the care recipient so you can have an honest, open discussion.

P stands for perception, which is assessing what the caregiver perceives about the diagnoses, prognosis and his or her ability to provide care.

The I is not so relevant, so we'll skip to K, and K is knowledge. This is where any clarification about misperceptions should occur, thereby educating the caregiver and imparting knowledge.

E is empathy. We may not all be caregivers, but certainly we can see that these caregiver superheroes have taken on a difficult, complicated task.

I believe that the P, perception, and E, empathy, are the most essential components of the SPIKES protocol as it relates to caregiver assessment.

Caregivers are not always gradually introduced into their roles. For example, in the wake of Hurricane Harvey here in Houston, we have seen elders who were previously able to live independently now lose their homes and suddenly require assistance and even relocation. So, being aware that caregiving might be an acute event rather than a long-anticipated one, you can see that the caregiver might have limited knowledge of the care recipient's health issues.

As an extreme example, rather than asking how long has your sister had HIV, it would be better to ask an open-ended question, such as tell me what you understand about your sister's medical conditions. You can imagine it might be possible that the caregiver not even be aware that her sister had ever been tested for HIV in the past. Again, it sounds so clinical, but, remember, you're trying to diagnose the perceptions of the caregiver. Your task here is to listen.

Further probing might be necessary. Anticipating the needs of each dyad is impossible. Another question I often ask is what do you find challenging about managing your family member's health. This opens a dialog whereby the caregiver can introduce his or her own concerns.

Think of the caregiver as a critical extension of the formal healthcare system. The efforts of a caregiver are the most important predictor of how well the care recipient will do. Complications such as pressure ulcers, malnutrition and recurrent hospitalizations are more likely to occur if the caregiver is overwhelmed and underprepared.

To maximize the effectiveness of the caregiver, it is essential to help him or her feel supported in his or her endeavors. I mean, even a superhero needs a little bit of love, so please don't underestimate the importance of empathy.

Caregiving is hard, and sometimes people aren't open to talking about it initially. So if the care recipient doesn't bring up anything when you ask, consider asking probing questions to delve deeper. As we mentioned earlier, tasks related to actual caregiving can be physically taxing, but there can also be nonphysical manifestations of stress also, and this is probably what we see more of.

As an aside, we should also be mindful that caregivers when placed in that role can actually flourish. Although less commonly seen than more of the negative emotions, we sometimes see that people have improved self-esteem and they feel better about themselves because they've mastered something and are making a difference.

The bottom line is when we start to ask questions and listen, then we can begin a dialog that has the potential to last years. In this process we also begin to normalize feelings of anger, sacrifice and fear, which can be reassuring to caregivers as they move forward in their role.

In the next few slides, we will briefly review some of the instruments that can be useful in caregiver assessments.

The Zarit Burden Interview is a validated objective measure of caregiver burden. It was initially designed for dyads dealing with dementia. The long version consists of 22 items, but a shorter

version also exists, and I would like to highlight a few items. Asking if caregivers don't have enough time for themselves, if they feel angry or that their own health has suffered are aspects of this instrument that are important in normalizing these feelings.

The Burden Scale for Family Caregivers was initially developed in Germany, and has been translated into 20 languages. It is not specific to dementia as the Zarit was. It is a 28-item questionnaire, and I like that it includes not only negative aspects, such as feeling forced to be a caregiver, but also positive feelings, like being acknowledged by others and even feeling joy.

The American Geriatric Society has another caregiver assessment which not only asks about difficulty concentrating as a sign of feeling overwhelmed and positive aspects such as feeling useful, but it also attempts to hit on an emotional facet of caregiving. There is a question asking if it's upsetting to see that your relative has changed so much from his or her former self.

Specifically for care recipients with dementia, there may be feelings of loss as the care recipient seems to lose all psychological attachment to the caregiver. I mean, imagine taking care of your parent with dementia who no longer recognizes you. Dementia can also be complicated by behavior issues like spitting, biting, screaming. These behaviors must have a psychological impact on caregivers, and they may be dealing with these feelings internally but not have an outlet within which to discuss them unless we specifically ask.

The needs and capacities of each dyad will vary, and if you keep in mind, again, a very clinical concept of diagnosing them, what they need and where they need to be, you can help fill in the gaps for them.

Next we'll hear from Allison Dobecka, who's going to take on what you do next once you've identified some caregiver needs.

Allison Dobecka: Hello, the first thing we're going to talk about is readiness to learn. There are roles for the learners as well as the teachers. The first role of the learner will be to be receptive, willing and able to learn. The role of the teacher is going to be understanding these needs.

As busy as we may be when we're in our teacher role, we must be willing to stop if the learning is not going to be effective. I would like to say that I feel like this is going to be rare, and there's rarely a time when there isn't something that a learner can take on.

Finally, we have to remember that timing is everything, and this is true in teaching. We need to make sure that the physical and psychological comfort is assessed to start with, and making sure that this is the right time to teach patients, make sure that we're not wasting not only our time nor theirs.

So we can use the mnemonic PEEK for this assessment.

First would be for physical readiness. As we heard about earlier, this is a task that we're asking caregivers to complete. It's going to be affected by the caregiver's height, weight, and age

difference. The physical demands of a bedbound or totally dependent care recipient can be daunting.

That would lead us to E, the emotional readiness. We're going to talk about in a minute the support system of the care recipient. Does the caregiver have a large support system or a small support system? Do they have anxiety of their own? What is their developmental stage? I know I have caregivers who sometimes are either a lot older than the care recipient or even a lot younger in where they are in their developmental stage for understanding this.

The next E is experimental. What are their coping mechanisms? How do they feel that they have control over this situation? What is their orientation of the situation? Is this a child who has lived a long distance away for many years, or is this someone who has lived maybe even with the care recipient in the same house?

The knowledge would be the last one, and assessing that is obvious, I would think. In my own role as a nurse, sometimes I've had caregivers who are also in the healthcare profession, and I assume that they may know something that we should never do, also making sure that they don't have different learning styles, written learning styles as what they prefer. Would they like something to be written, verbal, or maybe sent home for them to read later?

We all know the saying "it takes a village to raise a child," but the same can be for this patient population. We've already heard that the family caregivers make up most of who provides this care. Just to say this again, the informal caregivers are usually unpaid. They could be the spouse, partner, family member, friend, neighbor. Only one in four of these caregivers is going to get some sort of extra help from our healthcare system.

Again, the value of these services to these care recipients is massive. In 2013, it was estimated to be \$470 billion.

So, what can we do to help? We must get creative. The inner circle, of course, is going to be what we need to investigate. I encourage them, my caregivers, and even if the care recipients are with them, to think, list, brainstorm immediate family, extended family, friends, trusted community members.

We can move outward into our community, religious organizations, nonprofits such as Meals on Wheels in many communities, organizations such as the Alzheimer's Association, Parkinson's Association, American Heart Association for resources, not only for disease processes but the resources in the community.

The private or formal caregivers, private pay caregivers, is sometimes an option and can be explored. I know in Texas, we use the Department of Aging and Disability often for caregivers, but that will have a financial requirement.

Finally, I encourage patients, especially in what we heard about, the sandwich generation, to use the web to coordinate care. You can start very simple in using word documents to email calendars or group text messages. I know people can use Google Docs or shared doc systems to

make sure that everyone in their inner circle is informed of the needs. You can also think broader, such as with Facebook or other social media avenues. There are a lot of support groups out there.

Then there are also scheduling apps or scheduling websites, which are free. This really helps coordinate a group to be on the same page about the needs.

These are two online resources that I have recommended and have also used personally. On these, there is usually a care coordinator who sets up the website. For example, on the Lotsa Helping Hands, you can put requests for someone to drive the care recipient, make meals, put special occasions so that everyone's aware of. I know the Lotsa Helping Hands has an app as well.

So, with these websites and just in general we need to have a leader, a coordinator, a ringmaster, someone who's in charge and someone who's going to make decisions. Tziona's going to speak to that in just a little bit.

I think it's important to note, that this decision-maker needs to be present and available. Is this person going to have the ability to use the phone, email, the web, to coordinate the help needed? For example, let's say the head of a family is an elderly wife and the care recipient is the husband. Can she coordinate all of this? Maybe is there a daughter or son that would be better able to handle this task, and this person should be able to be the delegator.

Finally, speaking to this leader or coordinator and giving realistic expectations is important. There was a caregiver survey from AARP, and they asked caregivers to identify the main problem with the person they were caring for. The number one response was old age. So, these caregivers didn't know the exact disease process they were taking care of.

For example, if a patient is diagnosed with early dementia and their life expectancy is 10 years, this might have a financial impact on the decisions that they make. If there is a progressing neurological disease and the family sees, or the caregiver sees, that the patient is walking now, they might not understand that they may need assistive devices and mobility aids in the future.

If the caregivers are trying to decide where this person should age and if they understand that these future needs may change, they may better make decisions now.

This is just a brief case study of a 92-year-old I take care of with Alzheimer's dementia, and she had a pelvic fracture and has a history of extreme anxiety. She has six sons and one daughter, and she's lived with the daughter for many years. The daughter is also a small business owner, so she usually wasn't present for my appointments, but she is the primary decisionmaker.

While she would set up a schedule for her family to take care of the patient, even though I would be with the brothers or a sister-in-law during my visits, I always knew that I needed to call and check with the daughter, the primary decisionmaker and the leader. When this burden for 24/7 care became too great, they were able to pool money and sent the patient to a respite care two or three times a week.

This leads us to different support systems for our caregivers. Respite care was one of them. I spoke earlier of the Alzheimer's Association, Parkinson's, American Heart Association. Not only do they have information about the disease processes, but they often have education and training programs. They have support groups.

I know in our area in Houston, the Alzheimer's Association has classes for the care recipients to attend while the caregivers go to support groups or to training classes. There's also home modifications that often can be provided by churches or Boy Scouts. For transportation, I know we have a van service in our area that we help coordinate or set up our patients with.

I would also like to speak about family meetings. I know this can be very time-consuming, but these can give you big rewards by finding out the leader, making sure everyone's on the same page. In these family meetings, you may find that there are different cultural expectations of aging that might come up that you didn't know about before.

In the August 2017 Gerontologist, there was a study done that showed that while African-Americans and Latinos may expect less age-related functional decline, Koreans and Chinese cultures usually expect more age-related functional decline, so there can be a difference in perspective that can come out when doing these assessments.

In the last caregiver survey in 2015 from AARP, they found that still 60 percent of caregivers are female, but that means there is 40 percent that are male. Different issues regarding everyday care of a son taking care of his mother, such as being able to openly assess his needs or his questions is important to make sure that everyone gets adequate care.

I do house calls, so I see multigenerational living probably more often than in a clinic setting. I think it's great that we all know that children do better when they're living with their grandparents, and there's many rewards from that, as well as from the grandparents. However, there is a safety assessment that I think is important to bring up, meaning children around different equipment and medication, making sure that is secure and safe, and also fall risk, toys, things that are out, making sure the care recipient is in a safe environment, as well.

We heard about perceptions. I would like to speak about perceptions of placement. Again, open-ended questions is always good. How have previous family members or close friends aged? What do you consider aging in place? For some people that may mean care recipients being in their own home or moving to a family members' home.

In some cultures and in some communities, I've had caregivers who have never known anyone to move to a nursing home, so they don't know if that is an option for their culture or community. I think that's when it's important for us to educate on the differences between assisted living facility, personal care homes, nursing facilities, specialty facilities, memory cares, etc.

Again, asking open-ended questions about their previous experiences with people who are aging is important. Have they had positive or negative experiences when going to the hospital? Have they ever known someone who has been on hospice, and understanding that perspective?

In summary, assessing the readiness to learn is essential, along with making sure that we educate our caregivers on what help is available. Of course, our goal is to implement a tailored strategy that aligns with the family as well as the care recipient's preferences.

Now, I'll turn it over to Tziona Regev, one of our social workers.

Tziona Regev: Well, good morning or good afternoon. My perspective is a little bit different since I work in a geriatric outpatient clinic, so the focus is going to be a little bit different from the patient's perspective and then how does it impact on the caregivers.

So, in our clinic we see about 250 patients each month, and the majority of our patients live in the community by themselves. They may have some kind of support system, whether it's provided through the state or through family members. Sometimes it's long distance, but the majority are in their own homes, apartments, or by themselves.

What we've noticed, and I've been here at this clinic for a long time, is that the majority, I would say 80 percent, suffer from some form of cognitive impairment, and to various degrees on the gradient. There are those who have mild cognitive impairment to those who have advanced dementia to various degrees. It impacts the way our patients present themselves and what we need to do in order to evaluate and determine what will be the best intervention based on the presentation at any given time.

So, when we talk about cognitive impairment, usually we either see mild cognitive impairment among our patients, or we see some form of dementia, which, in many cases, translates into partial capacity. We perform decision-making capacity in our clinic, so this is on the gradient, when the majority of our folks suffer from some difficulties in their decision-making capacity. We can talk more about that and how does it impact, again, caregivers. What do we need to do?

When we talk about mild cognitive impairment, or MCI, the majority of our patients, when they tell us that they are forgetful, are functional. I actually had a patient just the other day, 60 years old, very vibrant, independent, and very functional with her ADLs and all of her IADLs, yet she proceeded to tell me that in the last few months she's noticed that she's forgetful with her short-term memory, and that sometimes when she cooks she forgets to turn off the stove. Sometimes when her husband reminds her to do things she doesn't remember, and she doesn't read anymore because she cannot retain information. Otherwise, she's very functional.

So, this is usually a presentation that most of our folks, even when they're mildly cognitively impaired, do not come forward and say to our doctors or to their family members or to their loved ones. It's rare that someone that is coming forward is aware and seeking some professional help to try to enhance their quality of life. The majority of patients do not, and that is the challenge that we're facing.

Usually when patients come here, they already have some form of dementia, or we may diagnose them if they're new to the clinic. What is early dementia or more advanced moderate dementia? Again, it can be Alzheimer's disease or vascular dementia or other types of dementia.

Usually, what we notice first is that there is some impairment with their personal care and hygiene. There is some impairment with their functional abilities, with their ADLs, and mostly IADLs, which is the instrumental activities of daily living. They may still be able to groom themselves and maybe dress themselves and ambulate and do all their personal care and hygiene. It may not be as good as we would like to think; they may fail taking their medications correctly, or they may fail to remember to pay their bills on time.

That is when we see some red flags among our patients. We conduct a geriatric comprehensive assessment, where the clinicians will do their physical exam and I do a comprehensive geriatric assessment that includes their cognitive assessment, their functional assessment and their mental health assessment.

For established patients, if we notice that there are some changes with their personal care and hygiene, such as stains on their clothing and such, we know something has changed. If we know that there is some weight loss and there is no explanation whatsoever, such as medical reasons, and we see that consistently, we know that this is a red flag to look further why is it.

Usually the issue is that we've noticed is that the patients forget to eat. Either they don't have the appetite to eat or they are not able to go through the motions to heat up their food or to remember to eat. That's executive dysfunction.

Sometimes they're just worried, they're concerned, or they're isolated. They pull everybody away from them. Mostly for those individuals, they have some mental health issues that they have been trying to manage and hang by themselves for a long time. Now, they may also compensate and compromise because they may have some executive function or early dementia or cognitive impairment. They may try to push away their loved one, their family members, their support system. Sometimes they're ashamed. Sometimes they don't want anybody to get close because they're afraid. They're afraid of the loss of their independence.

So what do we need to look for? This is really important. I think that the main concern is if we notice that patients come to the clinic with the same issues and regardless of what we recommend and how we educate them or their loved one, they keep coming back with the same symptoms, or they end up having multiple admissions to the emergency room. We know that their issues are not resolved, and we're trying to think what is going on. Why is it that there was no follow-up? What's going on in their home? What's happening that they were not able to follow through?

Sometimes it's a matter of not understanding the instructions, or they may have some cognitive impairment, which includes executive dysfunction that inhibits them of following through. We usually tend to label them, and I hate to say this, but we hear it all the time in the medical field as noncompliant. Those patients have a reason for the fact that they were not able to follow through.

Usually in the clinical setting when they see the doctor for 10 or 15 minutes in private sectors, we don't know. The doctors may repeat the same instructions over and over again, but they're

presented with the same symptoms. There is something deeper inside that inhibits them from following through.

Sometimes family members share concerns, and that's another way for us to know. I may get calls from family members, such as "Hey, my mom is more forgetful, and I think that she's financially exploited. The bills are not paid. What should we do?"

What is it that inhibits our patients? Why are they resistant to change? As I mentioned earlier, I think that the main thing is self-determination, the need for being in control. For many of our patients, they want to stay in their homes regardless of how compromised they are. This is what's familiar for them. They don't want anybody to interfere.

They don't want to reach out to people, to family members, caregivers and so forth, because they're afraid. They're afraid that somebody's going to take away their wife, someone's going to take their independence away from them or place them in a nursing home, or take them to the hospital. They're afraid. They'd rather push people away from them or not deal with it, so they avoid the doctor until it comes to our attention one way or another. I think that's the main thing; it is the fear of losing independence.

What we see mostly with these individuals, in terms of the manifestation of their behavior or their home situation, is self-neglect. The majority of the cases from studies that we've done here in the county and within the hospital are diagnosed among the elder mistreatment categories with self-neglect. That is the group that is harder to detect and is harder to intervene because those are adults. Usually the manifestation, again, is within the partial capacity where they still have a sense of what they want and can express it, but they have some gaps in execution and in the way that they take care of themselves.

So, where do we go from here? I think that the main thing is to try to work with the patient, with the person who is presenting those manifestations. So what we try to do is build up rapport and try to work step by step with our patients. We tell them how much we care about them and how much we're concerned about them, and yes, they're not going to a nursing home. This is not why we're doing an evaluation of their cognitive abilities. Sometimes I have to do a reevaluation because they're concerned; we need them to try to work with us to take care of them and to help them enhance the quality of their life.

I think that's the key component that we're trying to promote. It's about your quality of life. It's not about what I want. It is about being better able to serve you so that you can stay in the community in your own home. That is the first thing that we keep emphasizing with our patient.

I always ask on an initial visit from the patient if they can give me a name and a phone number for someone in case of an emergency, whether it's a formal support system or informal support system. Then I will ask their permission usually, unless I'm concerned about their safety, may I call such-and-such.

How can we manage to overcome challenges that we have in trying to engage caregivers or engage the recipients or the patients? In a specialty clinic, such as ours, what we try to do is

conduct an initial assessment on baseline, and then we'll have close monitoring. We may want to see them on a regular basis especially when patients exhibit red flags. We also work as a team, so it is important for us to communicate among ourselves.

What happens in regular clinics? I would suggest that either the patient or a family member will reach out to the doctor, share concerns and ask that they be evaluated for depression and/or dementia, or make a referral for a specialist, whether it's a neurologist or a geropsychiatrist or a geriatrician, just to look further into what's going on.

So, what do we do? How do we intervene? I think that the main thing that has been powerful, especially in our clinic, is to try to engage the caregiver in the process of evaluation. I may have the family member present during the cognitive assessment, the psychosocial assessment, the and mental health assessment, and they may notice when their loved one has difficulties.

I ask casual questions and try to tailor it to the educational level of the individual. Those questions, usually, and the tasks that they have to follow are basic. Do they notice that they have trouble with short-term memory, with processing information, or with recognizing shapes? Then, they are noticing there are some red flags.

When I conduct my psychosocial assessment, I also ask questions about their history. So we're looking to the long-term memory and the current memory. I ask questions about demographics. Where do you live? Those casual questions can raise flags and bring awareness to the family members that something has changed.

For long-distance caregivers, it is important that we communicate. Especially now with technology, there are many ways that I communicate with family members, via email, via telephone conferences and so forth. It is important to find a balance between the patient's rights for self-determination. How much can we engage and how much do we need to be involved? It is a fine line. How far do we go? How far do we push? How much can we allow for the patient to continue engaging in their functional abilities?

I just wanted to share a story briefly about a patient. It's a couple. They're both in their 90s. She's diagnosed with advanced Alzheimer's disease. The husband has been the caregiver. He himself is frail, with cardiac problems, mobility, physical deconditioning, and he wanted to be in control. Three daughters are involved, or semi-involved, living in different continents.

The daughter that lives here, whom they live with, they've been having tension. The husband did not want the daughter to be involved. Second, the finances have been depleted slowly. There's been a challenge in how to allow or try to convince the spouse to get some help from us and from the state and how to allow the daughter to step in.

I spent a lot of time with the spouse, who later on became one of our patients. So both myself and our geriatrician have spent a lot of time trying to cultivate the relationship and build up support. Eventually the wife became a U.S. citizen and started receiving provider care. We are right now looking into trying to get some help for him.

So, I'm shifting now to another issue that I think has been a challenge within our clinic, and that is how to navigate and access systems, whether they are in the local arena, state or federal. The majority of our patients have difficulties understanding the language and the intricacies that entails in benefits.

I'm going to go further and explain that sometimes the representative on the other side, because of the issue of HIPAA and privacy, do not allow other family members and/or healthcare professionals to intervene unless there is consent from the patient. Well, what happens when those patients are compensated? They are cognitively impaired or they have moderate to advanced dementia, and there are no provisions for power of attorney or durable power of attorney for healthcare. What do we do? How do we take it from there?

Some of the strategies that I've been using to try to empower either the patients and/or the family members is education. Share with them some written instructions. If we have a family conference, I will guide, in advance, the family member/caregiver on the phone in terms of the language and information they need to share so they are prepared with the Social Security number, Medicare number and also what to ask for.

I also try, on the other end, to educate the agency representatives. Usually they are young representatives. They follow a protocol that is regimented, which they have to abide by. I try to explain to them to try to think out of the box. Try to be a little bit more flexible, because we're dealing with patients that either don't understand what you're saying, they cannot hear you, or they cannot process, so you have to slow down. I see myself as being an educator. It's hard to work and navigate the system step by step with a lot of instructions and guidance on both sides.

An example I encounter nearly every day is when patients come in and all of a sudden something's changed. They tried to get their medications, and either they don't remember what kind of drug plan they have, or they did not enroll in a drug plan. I had a situation the other day of someone who was Medicare-Medicaid eligible, and now she's getting her widow pension, so she is no longer eligible for both Medicare and Medicaid. She is back to just Medicare, but it is in transition, and right now she doesn't have the benefits that she needs.

My role is to try to call Medicare and try to educate the caregiver in advance what we're doing, and what we need to look forward to. While we are having the conference call with Medicare, I have to get consent so they can talk to me and so I can ask the right questions. Sometimes it is a challenge, especially if the patient or the caregiver is not the representative's payees, and the representative on the other end are not convinced that they're getting the yes for consent.

So that's basically my role. I have added, on the next few slides, some tools that we use. This is the screening tool for MCI partial capacity No. 82, if I'm not mistaken. These are some of the tools that we use in our clinic in addition to ADLs and IADLs, and the PHQ-9 for mental health assessment on depression.

I think I have some references on the following slides in terms of where to get information about these cognitive screening tools. They have been helpful for us to conduct in order to get baseline information about cognitive ability, executive function and capacity. The MED-SAIL is a tool

that we here at Baylor College of Medicine Geriatrics and Harris Health have developed for our practices.

I'm going to pass on the presentation to one of our caregivers, Hattie Coleman. Thank you.

Hattie Coleman: Good afternoon. My name is Hattie Coleman. I am 70 years of age and have been a caregiver for my mom for over 10 years. She is now 103 years old. She moved here from Polk County, where she and my dad had been married for over 55 years before he passed away. After he passed away, she continued living in her home for many years until we decided she couldn't stay by herself any longer.

She was getting around good on her walker when she moved here, but as time went by, I went through a lot of challenges. First, she had a mini-stroke and recovered from that. Luckily, it did not leave her where she could not function. She was still able to get around on her walker. Then dementia started in, some days good and other days not so good. I had to learn how to deal with her in that condition.

When she'd get agitated, I would just leave her alone and go back to her later. She's really not able to communicate with you except the basics, and this still continues as of today. Then she fell and broke her ankle, and it went downhill from there. She had to have surgery, and that was a hard decision for me to make for a 102-year-old person, but I didn't have a choice. She couldn't communicate, so I had to make the decisions for her.

She was in the hospital two weeks. Then after the fall there was a much bigger change in her care. She went from walking on a walker to not walking at all and not able to do anything for herself. The support I received to keep her at home was a social worker who would come to assess her needs, provide equipment and supplies through her insurance company, which was United HealthCare. She developed a bad sore on the heel of her foot, and the home health agency would come to dress her wound and take vital signs.

Her insurance company would offer respite hours. She gets 700 hours a year, which I take them as I needed. The way I found out about the respite benefit was through a friend that was taking care of her loved one. I started inquiring about it through mom's insurance. When the social worker came out to visit her, she explained to me how it worked.

The respite care is perfect if you can find a good place. I've had several bad experiences with the places that I left her. Upon picking her up, I found her on the floor in the dark with the door closed. I said that's enough. No one should be treated like that, so I decided to do something different. When I have to leave her, I get someone in my home that I can trust to take care of her and so far that has worked out fine.

Out of all the support I've had, the house call doctor helped me the most. The doctor would come here so I wouldn't have to take her out for a doctor's appointment. The doctor would take time to talk to me about things that I would face while going through the healing process. I am so grateful that my mom is a part of the House Call Program, because home visits are so important and such a benefit to those who can't get around.

Thank you.

Caroline Loeser: All right. Thank you so much, Hattie, for your presentation, and thanks so much to our speakers, Dr. Major, Allison and Tziona for your presentations, as well.

This has been incredibly informative, and thanks for joining us today.

We have a few minutes now for questions from the audience. At this time, if you have any questions for our speakers please submit them using the Q&A feature on the lower left of the presentation. You can type your comment at the bottom of the Q&A box and then press submit to send it.

Dr. Major, I'm going to start with a question that was asked during your presentation, and I think, Allison, you might be able to answer this, as well. Are there existing measures used in healthcare that capture the health literacy skills of caregivers?

Anita Major: That is a wonderful question, and it would be a marvelous endeavor. I have not seen anything, and I find that the mix of cultures, languages, and expectations are so varied that the open-ended questions tend to work best for me. I have not seen anything objective or any scales that have been validated that attempt to get at that.

To understand those kinds of things you need a rich conversation, and I usually use the scales that I mentioned as sort of an introduction to start the dialog, but those I end up just asking as the discussion progresses. Allison, do you have anything to add?

Allison Dobecka: I would just add that I don't know of any scales, but time is probably the best thing to determine that, as you were saying, and with open-ended questions.

Caroline Loeser: Great. Thank you. Allison, while I have you, I have another question that came in. You talked about family meetings being key to helping families get on the same page. So should you have the care recipient present during these meetings or just keep these meetings for the team of caregivers?

Allison Dobecka: That's a really good question. I've had family meetings both ways, but I would say typically the family members feel more comfortable and are able to speak more honestly about their feelings. Typically this is a child speaking about a parent, and that has its own dynamics, so I think, while it's definitely up to the group as a whole to make that decision you would probably get a more open and honest conversation if it's just with the care recipients, in my experience.

Caroline Loeser: Great. Thanks. That's a great point. Tziona, I have a question for you. Where can someone go for a comprehensive geriatric assessment?

Tziona Regev: Here in Harris County in Houston, Texas, there are a few geriatric clinics. The clinic in which I work at has been probably the more comprehensive and the longest of all. This

is with Harris Health, which is a county hospital, in conjunction with Baylor College of Medicine, which is our staff.

I'm not sure what's available in other counties and other states. I think that the best thing to do is if the individual or the family member has concerns about their memory and the primary care doctor is not able to address those issues or doesn't seem to have the tools, then I would recommend that the family members or the individual ask to get a referral for a neuropsych testing and/or to a geropsychiatrist, a geriatrician or neurologist. Have any of those specialties, get a referral because there are concerns.

I think that is the main thing that I always share with either the patient or family members. Often the presentation of the patient is that there's nothing wrong with them. In 5 or 10 minutes, it is really hard to see and look through what's not said, or what's the observation. It's too short. That's why we take more time here. Our evaluation on an initial visit is one hour with the clinician or the doctor and one hour with the social worker, myself. Most clinics don't have that leverage or that time. So I would recommend sending to a specialist.

The main thing for either the patient if they are concerned and aware and/or the family caregivers is to keep a log and write down things that have changed, that are different, those red flags. What doesn't sound right with grandma or with mom right now? Share the journal by email, phone or face to face with the PCP and/or with the specialist if they're not available. Anybody else have something to add? Dr. Major?

Anita Major: You know, my experience in the healthcare system as a medical student, resident, fellow and now a clinician, I've always been in the academic realm. So that's really the only aspect of healthcare that I know. I know in any academic setting you have clinics, usually a geriatric presence, that would do these kind of assessments. I'm sure it's possible, and I'm sure people in the private sector also do a wonderful job. It's just harder for me to know where those are.

I have been asked for help finding people in Atlanta and Chicago and wherever else, and my first thing is to go an academic place. Whether that's correct or not, I don't know, but certainly they would have it at a minimum, and then I would expect other private geriatric clinics to be able to do these kinds of things, as well.

Caroline Loeser: Thanks, Dr. Major. That's insightful. Hattie, if you're still on the line, we have a question for you. As a caregiver do you have any recommendations for social workers who are doing the initial assessment in the home or when meeting for the first time? Is there anything that worked better for you when working with the professionals?

Hattie Coleman: Yes. The social worker was helpful to me as how to go about getting things for my mom that I would need at home. So it was a very good support for me.

Anita Major: Was it the fact that she came to your home that was helpful, or was it the questions she asked or the time that she spent? You didn't feel rushed? Was any of that better than what you would have expected if you'd had to go to clinic and leave your mother here?

Hattie Coleman: Right, by her coming to my home. That was a big help.

Caroline Loeser: Thanks, Hattie. So one of our participants asked that we talk about care plans and then best practices for communicating and providing to caregivers, collecting care histories and health status from caregivers, and then finally reducing stress, sharing caregiving, and improving communication for caregivers.

Allison Dobecka: Okay. So, for the care plans, like I said, I do house calls, so the way I practice is a little different. I feel that leaving something with the family or the caregiver is probably the best strategy. When I'm in the house, and I write my instructions or my care plan I physically tape it to the mirror, bedside table, the kitchen, or the refrigerator so that it's somewhere where the caregivers feel is the best place for everyone to see.

Even if you're in a clinic setting, you can make that reminder to not just put this in your purse and forget about it when you get home. Put this on the nightstand. Put this on the refrigerator. I have had families create books to keep track of things, but it's important to show them the importance of your plan. I hope that answers that question.

I'll go to the reducing stress. So, I was a nurse in a hospital for many years, and we as nurses talk about caring for the caregiver, meaning you can't do your best work at the bedside or in a clinic if you're not taking care of yourself, so remembering to eat lunch, etc. I try to take that concept into the home, as well. Oftentimes, my visit with a patient may be a small percentage of the actual time I spend total because families are feeling stressed or guilty for trying to also live their own life.

I think that is a time when, as Dr. Major said, the key is listening and also validating that they are also allowed to take care of themselves. At least in house calls, reducing stress for our caregivers does take a lot of our time. Even after just saying the concept "caring for the caregiver" their eyes can sometimes light up; it is as if they never thought of themselves as someone who needed care for.

Collecting the care histories and health status, I'll maybe send that to Tziona, because I know she does a lot of that, if that's okay.

Tziona Regev: As Allison mentioned, my role is to try to listen actively and be with the caregiver at all times throughout the journey. At times, since this is a clinical setting, the caregiver is present with the patient. There are times that the patient does not want the caregiver to be present, so I would ask, gently, to separate. I may have an excuse why the doctor needs to see the patient, and I will take the caregiver to my office so we can have a one-on-one conversation. It really depends.

I try to, first of all, listen to where the caregiver is coming from and what their concerns are. What kind of relationship have they had with the patient in the past or present? Sometimes there is unfinished business between the patient and the caregivers, and they end up being the only one, even though they haven't been close to the patient. It is really important to recognize and

understand where they're coming from, and what they are willing to give or how much they are willing at this point.

The other piece is to try to educate them about why Ms. Jones is not able to fix her meals, why she is not able to do so-and-so because often the family members will say, "Well, she's just not interested. She just doesn't care." My comment is maybe she cannot do it anymore. Maybe she is not able to. Maybe there is some executive function. There is a lot of education going on between myself and the caregiver.

The other thing, as Allison mentioned, is that I try to educate them about the fact that our patients are adults, so we try to engage in conversation with integrity and allow them room and space for self-determination. However, we also try to give the caregivers the legitimacy that this is very stressful; this is a journey and it is a process and it takes time. Sometimes we cannot do a whole lot until further decline is present.

We may mention to them again that you have to take care of yourself. There is a need for self-care. We also try to empower them. I think it is a combination of education, advocacy and trying to be there for them. We make sure that we are accessible; if they need to they can call me, they can email me, they can just drop in, which happens. We try to be available at all times. Hopefully, that answered the question.

Caroline Loeser: Yes, that's fabulous. Thank you. All right. At this time, Hattie, we have a couple of questions for you, so I'm going to ask you another question. It sounds like you were receptive to receiving respite care. Would you have any suggestions for how an "outsider" can go about convincing a caregiver to seek help such as respite care?

Hattie Coleman: Well, the way I've used respite care is to give the person that is a caregiver a break to get away because it is a hard job to take care of someone. The main thing for respite care and placing them somewhere is that it can be hard to find. You have to find a good place to put them, because, like I said, I had bad experiences with some of the places that I left her. So just try to pick a good place if any way possible.

Anita Major: This is Anita Major. I interpreted the question more as if a caregiver were reluctant to utilize that how would you discuss it with them. If that is the intent of the question, then I would add that you would need to, again, get at the perceptions, and say, well, what makes you nervous about this?

I will say, as a healthcare provider, sometimes we don't promise the moon, but we say, you know what, I'm going to get a home health nurse in here and it's going to be fantastic, or this respite benefit is so wonderful you should do this. I have learned to not be so excited about some of these things because the implementation of them is that, oh, I saw someone come to the door and they left a sticky on my door saying "sorry I missed you" but they never rang the bell. That was a physical therapist who just came and left and didn't even try to access the patient. Right?

So we have all these wonderful things that if they were implemented perfectly would actually relieve some of the work, but sometimes when we ask these companies to help us, it actually

creates more stress for the caregiver who is expecting relief. This goes back to getting a care history for asking what you have used before, what supports you have had, and how they worked for you.

If someone is resistant to utilizing respite thinking it's going to be dangerous for their loved one, or they've heard bad stories, or they don't feel like they've earned it, then explore those questions first so that you can better speak to them about how it might be helpful.

Caroline Loeser: Okay. Thanks, Dr. Major. I think that's a really important perspective. While I have you, we do have a couple of other questions directed for you. Do you complete any quality-of-life assessments with the family caregivers. I'm sure our other speakers can speak to that, as well.

Anita Major: In terms of a questionnaire, by the time we meet people on the House Call Program, we do a more open-ended assessment about what makes life worth living. If someone couldn't do those things, then would that change the way that you make decisions for them?

There are certainly quality-of-life questionnaires that our patients can't necessarily fill out, and therefore I've never had a caregiver try to do that for someone else. I've not formally assessed my own caregivers' quality of life. If I'm here for an hour in someone's home, it's probably 20 minutes I spent with the patient and 40 with the caregiver. I feel like it's easy in that long time to get an assessment of it.

The majority of who's listening is going to be restricted in their time. So I, again, would say you're going to get more in-depth information asking general questions than having a questionnaire filled out about their own quality, if I'm understanding the question properly.

Caroline Loeser: Sure. Thank you for that. Tziona, we have another question for you. What kind of education do you provide to the caregivers, if you could speak to that a bit more.

Tziona Regev: It really depends on the scenario that I encounter. For example, if the issue is dealing with navigating systems, such as Medicare, the state or their health insurance, then I would try to prepare or even make referral for provider services. What I try to do in advance is tell them the kind of questions to anticipate the caseworker will ask them, explain the criteria, and what the state is looking for, so they know the kind of questions to ask.

It is really important that the caregiver is present during the interview and the assessment because often when you talk to the patient, most will say, oh, I can do everything. I can dress myself, bathe myself, cook for myself and so forth, because this is what they want. They don't want anybody else in their business. They don't want any help.

Often they suffer from dementia and other comorbidities, so it is important to educate and empower the family members to be present and to ask and point out the right needs for the patient. When I make the contact with the referral, sometimes I would make the contact person as the caregiver. So that's for referrals for the state.

Same thing is if we're dealing with health insurance benefits such as Medicare. It is important for me to explain, and reference handouts that I share with family members to try to simplify the systems of Medicare and the system of Medicaid.

It is written in a simple manner, and I go step by step to show them and give them a copy. I explain this is what mom has, this is what we need to look into, and then try to break it down. Too much information is overwhelming, and they can't read the instructions or the booklets on Medicare. It's a lot of information. Often family members or patients will bring me a stack of correspondence from various agencies, and they don't know what to do. I provide education about concrete services.

The other thing that I focus on in my practice is education for dementia and for those individuals that exhibit cognitive impairment. I discuss what they need to do in order to try to work with your loved one step by step. I try to give them information about the dementia, the stage they are at or the specific kind of dementia the individual has.

I try to give them education about brain enhancement, especially with cognitive impairment, if it's early dementia or mild cognitive impairment. I have some exercises and handouts on how to enhance your memory. I try to give them information about creative ways to deal with the dementia, having some hands-on activities, looking at how can we connect, depending, again, on the level of dementia or mental health issues that we have.

If we have psychosis, I try to explain to them the manifestation. How do you deal with them? I do some demonstrations to them. What's the best way to work with them? I think it varies. Of course, I give them a lot of references to the community. The main thing is having that conversation face to face. I think that's the most beneficial for family members, caregivers and all patients. Dr. Major, or Allison, do you have anything else to add?

Anita Major: No. I think what you said is fantastic. I have one small thing. I think it is important, as we support these caregivers, to let them know that it's a continuing relationship. So you don't have to have an hour face to face. You could do five minutes and say I'll check in with you next month, and then another five minutes.

It's more of a long-term marathon that I think we should be striving for, and that is really when some of these issues can surface. It doesn't have to be all at one time, but I think if we commit to more of a longstanding relationship of support than we can make a difference.

Tziona Regev: That is the beauty of the House Call Program or the clinic. We have this ongoing relationship with our patients and family members; we tell them that we're available on many levels. I think that's real important. That's a good point.

Caroline Loeser: Great. Thank you. That was a really helpful response.

At this time if you have any additional questions or comments, please email them to our email address. It's RIC@lewin.com.

The slides for today's presentation, a recording and the transcript will be available on the Resources for Integrated Care website shortly.

Thanks again to all of our speakers. Have a wonderful afternoon, and thank you so much for your participation.