

DELMARVA FOUNDATION

**Moderator: Jackie Hairston
May 21, 2013
9:30 am CT**

Operator: Ladies and gentlemen thank you for standing by. Welcome to the Improving Care for People with Dementia Living in Nursing Homes Part One conference call.

During the presentation all participants will be in a listen-only mode. If at any time during the conference you need to reach an Operator just press star, 0. As a reminder this conference is being recorded Tuesday, May 21, 2013.

I'd now like to turn the conference over to Jackie Hairston, Project Manager, Delmarva Foundation. Please go ahead madam.

Jackie Hairston: Thanks (Mark) and welcome to all of you today for joining us. My name is Jackie Hairston. I'm one of the project managers here at Delmarva Foundation, your QIO for Maryland and the District of Columbia.

I'm pleased to be able to offer you this two-part series on Improving Care for People Living with Dementia in Nursing Homes. This two-part series was presented to the quality improvement organizations across the nation as we were preparing for this Phase 2 work.

What you will be hearing today will be part one of a prerecorded session that will give you a little background information on dementia, how care has been provided in the past and how we can improve the dementia care we provide today.

Part two of this series will be presented on Thursday, May 23, and both recordings and PowerPoint presentations will be posted on our Delmarva Web site in the next two weeks. Those Web sites for the District, www.dcqio.org; and Maryland, www.mdqio.org, so you can then share the information with your staff at your convenience.

Phone lines will be muted during this call and if you have a question that you would like to have our presenter answer please submit the question via e-mail to me or your quality improvement consultant and we'll send those questions forward to Dr. Wehry for a response.

Our speaker today, Dr. Susan Wehry, (unintelligible) is a board-certified geriatric psychiatrist and advocate for seniors and persons with disabilities. She has educated physicians, nurses, medical students, ombudsmen, policy makers and direct care workers across the country. She is currently serving as the Commissioner of the Department of Disabilities, Aging and Independent Living for the State of Vermont.

So we're going to go ahead and begin our presentation with Dr. Wehry.

Woman: (Unintelligible) it's over to you.

Dr. Susan Wehry: Thank you so much (Kelly) and thanks all of you who are joining the conference here today. This is a really extraordinary opportunity, I think, that

we all have to really bring together many different lines of initiatives; many different activities; many different concerns within improving quality in nursing homes, all, in some ways, coalescing, for the moment, around a specific goal of reducing inappropriate or off-labeled use, inappropriate and off-labeled use, of antipsychotics.

But you can see from the Webinar that we have actually stood back and taken the broader view that this opportunity, this focus on antipsychotics, has really afforded all of us because ultimately what we're really talking about here is participating in what I see as a true opportunity to transform and improve the way we deliver care to people with dementia who are living in nursing homes.

I'm so grateful to (Kelly) for inviting me to participate in these - this two-part Webinar series because this is an area which has really interested me most of my - practically I guess I should say all of my 30 years as a geriatric psychiatrist because it has been my observation that we have over relied on medications, that we have been overly disease focused and we have missed many opportunities to really look at improving the lives of people with any disorder living in nursing homes. And so I'm very grateful that we're joining in this together and that we have an opportunity to look at it again.

My goals for this two-part seminar is quite frankly somewhat immodest. I truly do want the outcome of this to be to first transform your thinking and then have you join me in helping to transform the way care is delivered, what our goals are, how we look at quality improvement and how we look at continuous quality improvement and creating cultures of quality within nursing homes.

And I hope that you will be inspired to take that up and be able to inspire others. I also hope to just review with you some tools that we commonly use in taking on this kind of quality improvement activity.

As a person who has been involved in teaching for a very long time I know that working with adult learners, which all of you are, requires a willingness on your part to really stretch yourselves, to really look at new ways of doing business.

As adult learners all of us, myself included, tend to be attracted to Webinars like this or to learning opportunities that we go to to see if we're kind of on the right track. Those of us with lots of experience are used to working, used to mostly getting things right and used to having some tried and true things that we always do when they're not going right and we fall back on that. And that's not a bad thing. That's actually a good thing.

However, when it comes to really being receptive to new information in a field like long-term care I have found that people need to be willing to set some of that learned and lived experience aside and actually stretch themselves and see is there something new out there that even if things are going kind of well enough from where you sit could they maybe even go a little bit better.

So I ask you to stretch yourselves and I ask you as I'm leading you through this Webinar today and then again in a couple of weeks, or I guess maybe it's next week, or when we look at part two of this Improving Dementia Care in Nursing Homes, I really hope that if I say something that doesn't comport with your experience that seems to be at odds with something that you believe to be true rather than dismiss everything else I say, which will be the temptation, make a note of it and please let's dialogue during the Q&A

because that's how we're all going to learn and how we're ultimately going to make things better.

Here are the key points, the takeaways, from the two-part Webinar series. First of all it's a brave new syndesi world and I'm going to tell you what syndesi is momentarily. I believe that continuous quality improvement efforts, (WOPE), the whole quality world and person centered care, are very natural partners and embracing one allows us to create new cultures of continuous quality improvement and new cultures of person centered care.

Dementia care is clearly undergoing a transformation where the emphasis is shifting from what I call patienthood to personhood and this is really about a new emphasis on looking at who a person is, as well as focusing on what he or she has.

Probably the biggest development in the area of dementia care has been in the last 5 years from the work of (Jessica Cohen-Mansfield), who has really dedicated her 25 or 30 years of work in this area to looking at, initially, non-pharmacological intervention and addressing the behavioral manifestations of dementia and other neuropsychiatric conditions and really begun to shift to understanding behavior rather than just explaining it. And in the last five years she has really pulled this together, I think it's about the last five, culminating in a way of looking at behaviors as communications upon that need.

Now this may not sound like a particularly new idea for those of you who have been working in the field or those of you who have been working quality in the field because forever we have known that certain kinds of behavior, like mental status changes, may communicate something about constipation, may communicate something about pain, may communicate something about being cold or too hot.

What has shifted is, or what has been expanded in that, is looking at behavior as a communication of unmet core human needs, like a need for love, like a need for attachment and how that impacts the behavioral expressions in nursing homes.

And then finally a thing that will be reinforced is that unnecessary antipsychotic use not only can, but should be reduced and we're going to go over the tools for making that happen.

In part one I'm going to very briefly describe in about five minutes the way I think about the current landscape of long-term care, reinforce why transformation of dementia care is necessary, why I think this initiative to reduce inappropriate medications is so important, and then conclude with what we know about what to do and about how to do it and then leave you with some additional resources.

In part two we'll continue the conversation. The theme I'll be introducing today is this notion of practice shifting from dementia from the outside in, which is a way of looking at dementia in terms of its medical model, in terms of its symptoms and has as its basis explaining behavior.

We're going to make the shift at the close of today's talk to how we're going to use looking at dementia from the inside out to inform our new practices. And in dementia from the inside out the goal of our observation is not just explaining, but it's understanding.

And the reason this shift is so important is that understanding the unmet need and (understanding) of behavior communication actually allows us to take the

next very important step of moving from just intervention to moving to (prevention).

In part two we're going to further expand our tool box and that is going to be for nurses, doctors, nurse practitioners, nursing assistants, direct care staff, anybody who comes into contact with a person in long-term care, including maintenance, dietary, activities, social workers and so forth.

We will look at the evidence around the non-pharmacological interventions, talk about some new educational approaches to teaching this sort of philosophy of care to all caregivers and then we will conclude in part two with when it is appropriate to use pharmacological interventions and how it is appropriate to do so.

So the landscape of long-term care what do I mean when I say it's a syndesi world? Syndesi is a great word that I actually just learned this summer and it literally means a conjunction. It's from the Greek by way of late 17th Century Latin, for those who really like the history of words, and it's a term that has been used and has been sort of applied all of the time in astronomy and literally it means a conjunction. In astronomy it is used to talk about an alignment of sun, moon, stars and planets.

And I heard it at a Pioneer conference this summer in which the participants and attendees at that particular conference were really struck by how much of what we have all been doing through most of our professional careers around quality of care and quality of life are really beginning to converge and really beginning to become aligned.

We have all been through the frustration, and perhaps nobody more than folks in the QIOs, of sometimes it seeming, and I know it seems this way in nursing

homes, that we are just always doing the initiative of the moment, or now seeing us as focusing on this and now we have to focus on (unintelligible).

And let me pause for a moment to say to the Operator that we're hearing somebody's sidebar conversation.

Operator: Yes ma'am. One of your speakers is talking on their phone.

Dr. Susan Wehry: Okay. Maybe if you can get a message to them to tell them? They might appreciate the privacy.

Operator: I can mute all other speakers for you at this time.

Dr. Susan Wehry: Okay that would be great. So sorry about that for the rest of you, but I was hearing a lot of sidebar conversation and including with some occasional swearing that I was afraid might embarrass the speaker when she eventually found out.

So back to syndesi, great new word, so syndesi in astronomy is this alignment and we coopted the word this summer when we were really struck by the number and kinds of initiatives that are fully aligned for quality of life in nursing homes.

So let me tell you the ones that I think are aligned. First of all I think that the Institutes for Health, IHI, or Health Improvement; and the Science of Improvement, has made great contribution to the field. And the little logo that I have on the slide there is really just a reminder from their Web site as to something really familiar, the (Unintelligible) way of doing quality improvement.

There is nothing magic about this. Folks in QIO know that it is important to do precisely that, come up with a plan, try it out, test, retest, model/pilot, whatever language you use or whatever framework you use the basic message of the signs of improvement is that, one, there is a science to it and there are tools that we know are more likely to result in quality improvements than other tools.

So (balance) has been a great contribution to a field of quality improvement I think, which should not only have a strong evidence base, but just had some good ideas and we all tried different ones. The culture change movement, which itself runs the risk of becoming a cliché, so nobody ever knows what it means anymore, is also aligned, I think, with much that's going on

And culture change in the sense that I am using it really describes at its core the shift in the nursing home culture from an institution based focus to a person centered focus. And there are a lot more things that we could say about culture change, but for me that's kind of at the heart of it that we move from kind of things happening on the institution's schedule and with the institution's goals and moving much more to a model that talks about the resident's goals, the person's goals and that they direct their destiny, so to speak.

MDS3, also moving in this direction of putting the resident's voice in there, focusing on quality of life and not excluding quality of care, but certainly broadening quality of care to include this notion of quality of life. And it's putting the notion that who defines the quality of life is the resident themselves.

The whole Advancing Excellence campaign further reinforces that voluntary notion of we don't want to do just a good job, we want to do a great job. We

don't want to do just a good job today; we want to build the systems that allow us to keep doing good work. And the QIO throughout all of the scopes of work, the new (WOPE) coming from CMS, all of this is what I mean by syndesi.

This is particularly true around the initiative now to improve dementia care in nursing homes. But before we go into that, five minute quick review on what dementia is because not knowing who's all on the phone I didn't know if we had common language, common grounding.

But here's how I want us to think about it and what I want to remind us of with respect to its characteristics. I've elected to use the DSM4, which is the Diagnostic and Statistics Manual 4th Edition of the American Psychiatric Association, as sort of the Bible or the basis that I'll use for a diagnosis, I mean for describing it.

Remember first of all that dementia is a syndrome. It's really not a diagnosis. Dementia is an umbrella term used to embrace many causes of dementia. But across the board it has as the common characteristics a condition that is acquired. It is not - you are not born with it, you get it later on in life, it is progressive and the cognitive feedbacks or deficits are manifested in key areas, one amnesia, the first of the five A's; secondly, aphasia, or problems with speech and communication; apraxia; agnosia; (agulia). For the five A's some (unintelligible) syndrome of dementia.

And (agulia), for those of you who aren't real familiar with that term, refers to really kind of disturbed executive function, a frontal lobe function, it means literally without the will. And I like the word because it makes for a nice pneumonic and nice alliterative five A's.

So those are the primary symptoms and that collection of symptoms in order to be diagnosable, if you will, must also significantly impair social and occupational function.

And then as it always is in DSM this condition, whatever it is, cannot be due to something else, some other central nervous system; some other physical condition; or act as one condition, like schizophrenia. So we're talking about something that has as its core memory problems and then other disturbances in cognitive function.

I also like to remind us, although this way of kind of separating dementias is becoming a little old school, but basically dementia in my mind really does have a reversible and irreversible field, if you will. And the reason I like to remind myself of it is that not all things we see that fit the syndromal definition or description of dementia are irreversible.

We have tended to move toward the direction of irreversibility across the board and we only think of dementia as irreversible. The problem with this, from my point of view, is that I've seen many people who come into long-term care, post-surgery, usually have fracture, some other fracture, who have developed actually a delirium, which goes into a kind of sub-acute phase and they definitely have all of the clinical characteristics of the syndrome of dementia.

And because it doesn't remit quickly it tends to be seen as a dementing illness. Some of those are reversible; some of those are protractive responses to adverse drug reactions, usually from anesthesia, plus whatever is given for disturbed behavior in hospitals.

So I want to always remind relatives and remind all of us to keep open to the possibility that the dementia that we think is irreversible is actually reversible. That said, excuse me, that said, most people living with dementia in nursing homes do have irreversible dementia. The majority will have that.

And remember with respect to dementia that Alzheimer's Disease is far and away the most common kind of dementia. It is a degenerative disorder. It probably accounts for between 70% and 80% of all cases of dementia that we see in long-term care. The other most common kind is vascular dementia, which is non-degenerative and used to be known by the term multi-infarct dementia. Those two together, a mixed form of dementia, account for a significant portion as well.

For the sake of completeness here are some other types of irreversible dementia. And frankly if you're a consultant or working with consultants through long-term care facilities knowing what kind does make a difference to a certain point because each of these kinds of dementia have slightly different flavors, if you will, or slightly different emphasis in terms of what kind of symptoms are going to be most present.

And to the extent that knowing a diagnosis helps staff become less judgmental about behaviors I think is worthwhile. To the extent though that we're trying to expand on our way of looking at dementia to move us beyond the diagnosis I don't want to be too fixed on saying this is the most important thing it's just one more piece of the puzzle.

Just to ground us in how big this problem is, one in eight older Americans have Alzheimer's disease. Looking at the graph you can see that that's about 6 million people and in another 40 years it's going to be about 14 million

people. If you like percentages better, 1 in 8 is between 13% and 14%. But that's the magnitude of the problem.

Any kind of dementia, Alzheimer's disease or one of the other types, increases significantly the likelihood of living in a nursing home, it increases disability, it reduces the person's independence and activities of daily living, and increases the use of medical care.

So from the chair I sit in now as commissioner, as opposed to as a clinician, this leads me to appreciate the tremendous healthcare cost and burden of this disease, as well as the burden in terms of quality of life for the person who has the syndrome or who has the disease of Alzheimer's.

About half of elderly nursing home residents have dementia listed in their record. And one of the reasons I quote specifically, and that's a, AHCA, American Healthcare Association statistic, one of the reasons that I quote specifically from that is to remind me and to remind you that when you're trying to look at the data around dementia you really have to be really careful about what people are using as their descriptor.

Because what's happening in the field now, I think, is that we're increasingly kind of bringing the numbers in, certainly the Alzheimer's Association does this, looking a pre-clinical kinds of dementia as well as a way of emphasizing the magnitude of the problem.

On the other hand, if you're Medicare, you look at it in terms of whose submitting claims. And so you look at the age group as the 65 plus. If you're just sort of interested in the big picture you might just go to the medical record and say, "How many people have it listed?" And that gives you a starting

point knowing that not everybody has all diagnosis listed in their record and some people might only have the diagnosis that got them admitted.

So just pay attention, but I think with all of those caveats what I think it is fair to say that somewhere between 1/2 and 3/5 of people in nursing homes may have dementia disorder.

For years I have taught about dementia and what is captured in this slide and that is that biological and psychological symptoms of dementia occur in about 90% of all people who have Alzheimer's disease. And as you can see on the slide there you can sort of follow across the life of the illness when they are more likely to show up or to be made manifest.

And these behavioral symptoms in most of the literature up until very, very recently have sort of dominated those of us who have looked at both pharmacological and non-pharmacological ways of addressing this syndrome or the disease of Alzheimer's disease.

Again I want to be very clear that in trying to help us make the shift to transform our approach to dementia care away from a dominantly medical model I don't mean to make it an either/or, it's sort of more in advance down the continuum.

Knowing this is helpful information, but the way we understand the prevalence of these symptoms, I think, is what's shifting. We're also throwing out this data, but we're saying, "Maybe we can use it to look at things in a new way."

As I said, upwards of 90% of people with dementia may have one of these behavioral manifestations over the lifetime of the illness. And for those folks

with dementia who are living in the community cared for by their caregiver, often a family member, it is as likely as not that that behavioral disturbance will precipitate the nursing home placement.

Interestingly when you sort of look at, you know, what's the tipping point for a lot of families incontinence used to be the tipping point for many, but that's really not the case in terms of dementia care and in terms of people who have been cared for at home. It's really these behavioral disturbances and psychotic symptoms that get people into nursing homes.

And this is also why that 50% of people who are currently in nursing homes on antipsychotics and have dementia come in on them. So these are not drugs that are necessarily being started. They're started in the community because dealing with behavioral disturbances and psychotic symptoms are really what adds to a significant part of the burden for family care givers. So these are really confounding kinds of symptoms.

One of the ways that I look at long-term care, again having been in this for 30 years, I'm very impressed with how much more knowledge we have and how the expectations have changed on the part of regulators; on the part of people who live there; on the part of their families; and frankly on the part of caregivers and care providers, what the expectations are around that work.

One that I have already mentioned, we have moved to a person centered, person directed world. One of the next advances in this, I think, and one that I'm beginning to emphasize more and more, is the notion that being person centered and being person directed does not mean being person isolated.

That even though we honor the dignity, the completeness of each adult, even though we honor and support their autonomy, their direction of their care plan,

their voice at the center of all things, we need also to recognize that most people live in a context, live in a context of relationships, these may be friends, family, co-workers, they may be somebody's parents, somebody's son, somebody's daughter and so forth.

And looking at people in the context of their natural circles is, I think, the next step in this whole person centered, person directed world because it is acknowledgement of that broader community beyond, or as part of, the nursing home world that I think actually there's some evidence that suggests results in better outcome.

So person centered, person directed relationship based care is the name of the game. There's not a debate about this anymore, so some homes have succeeded to - I mean homes have succeeded to varying degrees in terms of really going through the organizational shifts to make this a reality.

The second thing about culture change, and it's the second to change the expectation and frankly change knowledge, is the notion of what constitutes feeding people, thus the circle at the top obviously points to, for those of us who have been around a long time, what used to be considered sufficient and good care. That is to say it used to be considered sufficient and good care to get meals to people at the right temperature with the right number of calories and avoiding any foods which they might have an allergy or hypersensitivity.

That food of the past with that whole model of trays and covered plates and surveyors coming in and making - sticking thermometers in everything, it's not that we don't care about those things, but what we now know is that having food that looks like food results in less food waste, it results in better nutritional outcomes and greater pleasure, one might assume, from having food that looks like food.

The next step in that evolution is to actually have food cooked on the unit, so not only do you get food that looks like food, you get a meal time that smells like mealtime.

In terms of individualized choice, individualized routines, the fellow reading his newspaper, captures the sentiment, captures the notion, that people do have their individualized routines, their way that they've always had breakfast or had a particular meal. And it actually turns out that the evidence is pretty strong that individualized, sorry, that individualized care plans and individualizing a person's routine within the nursing facility actually results in better outcomes.

I started to go ahead to the next slide. I thought it was in there, but I see that it is not. And these outcomes include things like, fewer pressure ulcers, less vegetation, less depression and improved sleep. So this again is not just wouldn't it be nice, it's really isn't it better, better health outcomes, better quality of life.

One of the biggest advances, I think, actually was triggered, and I'm sorry the slide is reversed, but the picture that's attempting to be captured is to error is human. And this is the monograph that was written back in 1999 by the Institute of Medicine who when they did their national survey and were alarmed by the number of errors that were being made in hospitals and in acute care settings.

But we're talking about the headlines kind of errors. We're talking about wrong limbs being amputated, we're talking about wrong kidneys going out, we're talking about the egregious headline capturing kinds of problems with health and safety in acute care settings, particularly hospitals.

And it was noted at the time in the Institute of Medicine report that there had been within hospitals this kind of emphasis on who screwed up when things did go wrong. And that the mission, if you will, of the quality assurance, or the intervention, after an event was to find out who had done something wrong.

That study really began, I think, the shift away from who did what wrong to a culture of quality and safety that said error prevention is really what we should be doing. It's not just who screwed this up, it's how do we keep it from ever happening again, or more specifically and in a more modulated way, what process, what systems, would make it less likely to happen again knowing that we can't eliminate all risk?

So I see To Error is Human, the 1999 Institute of Medicine report, as really ushering in the new way of thinking about cultures of continuous quality improvement where the constant mandate and the mission within the nursing home within any healthcare system is to constantly be asking the question, "What can we be on the alert for? What can we report back? What can we do to keep making things better?" and to prevent mistakes and to prevent bad outcomes from ever happening.

The other big advance in our body of knowledge in long-term care, I think, is all of the work that was started by (Susan Eaton) and carried out by others, which really demonstrates that quality of the workplace is critical to the quality of care. You'll hear this sometimes said as (unintelligible) staff give better care. They do. Good staff, good care, happy staff, happier residents.

And in the area of dementia care one of the areas that I think we have not - dementia care is one of the areas in which our training has not really kept

pace. And so the care of people with dementia, particularly those who have some behavioral expressions, results in an expression on many staff's face something like this, "I'm ready to pull my hair out. I don't know what to do. I need better tools." And when people don't have better tools they reach for PRNs.

The data on better jobs, better care is also very strong. Fewer falls, fewer pressure ulcers, fewer acquired catheters, less nurse turnover, less absenteeism and high occupancy when staff feel valued and respected. I've heard this described as culture change 101 and that's really what it is.

The other change and expectation and the other development, I think, that's part of the syndesi world is the way surveyors are being encouraged to look more closely at unnecessary meds. They've had (Best) (Type) 329 for a long time. It really refers to unnecessary meds. And now that's a tool that's being used to look at antipsychotic medications.

In my view because the increased prevalence of dementia, just because we are such an aging society, particularly Alzheimer's disease, is leading to an increased demand, increased pressure, increased burden on our healthcare system, or to put it in a different way, increased opportunities in our healthcare system.

It's resulting though in greater staff burnout and in facilities with high proportion of people with dementia who do not have specialty training sort of at a (rate) for (hire). Medical costs and hospital admissions are higher in people who have dementia living in nursing homes given our current way of caring for them.

And then finally the off-label use of antipsychotics has gone up despite the FDA black box warning. So what did it basically say? In 2005 the FDA said, “Elderly patients with dementia living in nursing homes who receive antipsychotics for agitation are more likely to have a stroke or die than those without dementia and those, I’m sorry, those not prescribed antipsychotics.”

They also noted the time that antipsychotics in fact are not FDA approved for behaviors associated with dementia. Moreover, there is no anti-agitation drug that is approved. There are no psychotropics that are FDA approved for behaviors associated with dementia. And despite that, despite that black box warning, and despite it being off-label, prescribers continue to prescribe antipsychotics and other psychotropic medication.

Finally in 2011 in an effort to try to get through some data (JAMA) looked at 38 randomized controlled trials about whether or not antipsychotics had any utility. And they looked at that again because we have the FDA warning, we have this increasing press awareness of limited efficacy of these medications, we have the people that are dying, these drugs aren’t effective and they hurt people. And so, you know, (JAMA) looked at this and said, “Well let’s see if we can get to the bottom of this.”

At the same time the Office of the Inspector General was looking at atypical antipsychotic drug use and found that 83% of clients were associated with off-label conditions and 88% of those were associated with dementia, which of course is what is specified in the FDA prohibition, or FDA black box warning, not prohibition.

So we’ve got an intervention that doesn’t seem to work all that well that seems to have a risk benefit (fallacy) in the wrong direction, we have an FDA warning and we still have these drugs being prescribed.

And so the idea was why is that happening? CMS has pulled a group of experts together and basically these are commonly sighted reasons, physicians aren't aware of what else is out there. So when a physician gets a call in the middle of the night they use what they know. At least treat something temporarily, or at least quiet the situation. So there's a lack of an awareness of what's out there by way of evidence, non-pharmacological strategies that might actually work.

Definitely a lack of staff training in alternative approaches to challenging behaviors and then some cite, I'm not sure that I agree, but some cite the lack of available geropsychiatric consultation as another commonly cited reason for using drugs.

So CMS responded to this whole collection by launching the partnership last March, a partnership to improve dementia care and set as a goal reducing avoidable antipsychotic use by 15% at the end of this year.

So I want to emphasize on behalf of CMS and on behalf of the rest of us who are interested in this that this sort of narrow and maybe not necessarily the most well-defined measure was an effort to actually put up the goal post, put up a sign post and say, "Let's shoot for something and let's figure out what it would take us to get there. And the something we're shooting for is the 15% reduction by the end of this year, but it is not intended to stop at the end of this year and in fact it's only a springboard to the larger goal of improving dementia care."

I can tell you, for those of you who participate with facilities, in trying to address this improving dementia care and reducing antipsychotics the number one challenge is the belief on the part of everybody that antipsychotics

actually work. So part of addressing that is to make sure that people have adequate data and adequate information.

There was a study published in 2005 in the British Medical Journal by Clive Ballard, which showed pretty convincingly that not only is there no benefit with Quetiapine, one of the more popular antipsychotics that's prescribed, there's actually some evidence to suggest that it hastens cognitive decline.

The (JAMA) study, I've already mentioned, shows that the effectiveness is quite weak and that was published in 2011. And this study that was published in Neurology in 2009, again by Clive Ballard's group in Great Britain, shows this - showed the lower survival rates in people who were taking antipsychotics, specifically people with dementia, particularly people with behavioral disturbances.

Dr. (Unintelligible), a colleague at Harvard, sums it up this way in terms of the net effectiveness, "For every 100 patients with dementia who receive an antipsychotic medication somewhere between 9 to 25 will benefit and 1 will die." That's kind of a stark statement, but it is a way of trying to sum it up for families and prescribers that may capture all of the data in a way that we can begin to challenge that belief that these medications work.

Why do people die? For the reasons you might expect, pneumonia, stroke, pulmonary embolism and sudden cardiac arrhythmias with pneumonia clearly topping my list. And a major mediating factor there, I think, is the dehydration and over sedation for which antipsychotics are known and in fact it's why they're often prescribed.

I think we have states from all over and I'll let you, when you look at the slide deck later, find yourself on this graph. This comes to us by way of the

American Healthcare Association, AHCA, and you can look it up also on their Web site where they have a lot of tools that I'll mention in a moment.

So what do we do about this? I'd like us to embrace what we can do about this in this spirit and I think that this is an important frame to offer nursing facilities as well who in some ways are completely, or frequently, under siege where everybody telling them ways they could be doing things better.

And for people who have given themselves to this work for a lifetime hearing that they've been doing it wrong, or hearing they can do it better, often gets translated by them that they've been doing it wrong.

So I often kickoff my conversations by saying, "Look we've done the best with what we knew. We've done a good job. But now that we know better we have to do better." And an example of this that I think is worth fighting is this - is what we did with (posies). I've been around long enough that I used to write orders to tie people up as a way of allegedly keeping them safe.

And it wasn't until the field made the connection between increased injuries, increased pressure ulcers, loss of muscle tone and more complications that are helpful intervention that were effective that we stopped using (posies). We weren't bad to use (posies), we weren't wrong to use (posies), we didn't have enough data. We did the best we could with what we know. Now that we know better we really have to do better.

I think your starting point is to engage leadership and that's going to vary within the cultures, the cultures are going to vary within the very (unintelligible) company you work in. And in some ways that, you know, there's the culture - I mean there's the leadership that is the administrator; the director of nurses; there is the director of social service; there is the MDS

coordinator, or whoever the leadership team is; and certainly the medical director. There is also in every facility an informal leader. There is the person who is the go to person and in my view that person should also be engaged.

But to make change in this it really is starting at the bottom, starting at the top, reaching people in between, but finding the leadership team and engaging them in trying to make the change. I think because, as you will see towards the - in the next five minutes here and certainly in Part Two, much of what allows us to be successful in a new transformed world of dementia care is starting with organizational practices, organizational processes.

One of the key practices that has shown to have a lot of effectiveness is consistent assignment. While that means different things in different facilities when I use the term here an existing assignment has been study it really refers to a caregiver being assigned to a person, not for a month, but for the duration of their stay, to the extent humanly possible, for the purpose of building a relationship. Because relationship based care is what allows us to anticipate and meet needs rather than waiting for a behavioral disturbance to tell us that we failed to.

Culture change processes, lot's written on that, you can find out about it. Environmental assessments, we're going to touch on today and then again in part two, are a part of creating environments in which needs are more likely than not to be met, these core human needs, as a way of preventing rather than intervening with disturbing behavior or distressing behaviors.

I said I think current care practices is a key starting point, I think, of any effort to transform dementia care. And again, the one for which we had the best evidence, I think, is the notion of individualized routines. And then staff huddles, and then I should have another bullet up there about staff

communication tools, or effective communication, staff to nursing, nursing to doctors and then routinely monitoring data.

Some of the benefits of this improving dementia care through this door of reducing antipsychotics, I think, is an opportunity to further embed culture change. We expect to have fewer accidents, fewer injuries, certainly improving staff satisfaction if we actually know what to do. It should result in fewer residents being under inappropriate antipsychotics.

And frankly I think that it wouldn't be unreasonable for us to expect to see penalties as another tool for furthering this goal of reducing inappropriate use. And so there should be a way of avoiding that potential.

On the AHCA Web site, one of the resources that I want to point out to you, there is a slide deck from Georgia that I think is particularly useful. This is the way they talk about keying a change process within a nursing facility and some of you may be familiar with this. I don't think this focus tool is new with them, but it's a nice convenient way to organize, I think, getting started in this process.

What doesn't help, but what usually happens, is finger waving, finding fault, with whose fault is it that the psychotic use is so high. If you ask doctors they point to nurses, if you ask nurses they point to direct care staff. You get the picture here. Everybody blames somebody in the nursing home world as to why people get on antipsychotics and we want to shift that conversation not so much to look at who's at fault, but to look at this cycle, if you will, as a process and to use it to focus on interventions.

I'll give you an example. We know that 50% of people enter on antipsychotics. We could say therefore, "Well that's the fault. That's the

hospital that puts it on or it's the doctor in the community that's putting people on antipsychotics and then they're on it when they come in."

Another way to approach it is to say, "That's a good place for us to start. We could look at people who are coming in and we could decide to do a review in a very focused way of all of the folks who are on antipsychotics coming in and see if there's something about our venue, our care environment, that would allow us to take it off the person."

The other piece of data we have that might allow us to focus in a meaningful way is we're finding that where homes already have higher rates of antipsychotic use there is a higher risk that a resident will be put on an antipsychotic within the first 90 days of admission.

Picking a target, picking a measure, being successful is a great way to go. Nothing succeeds like success. The measures that are recommended by AHCA as one place to start in this quality improvement initiative around reducing antipsychotic use is to look at a measure around incidents and a measure around prevalence. This is a little bit different than the way you will see CMS measuring it.

And there are lots of conversations going on about what's the best way to do this. I happen to think that this is a really nice way to begin, but to really look at the percent of individuals who have had an antipsychotic drug started or an off-label use, within the first 90 days and to use that as the numerator of all people who are on an antipsychotic to try to figure out whether we can reduce that percentage by just focusing on that group.

The only group that you could focus on are folks who have started on it at the PRN and then ended up being on it for a longer period of time. The prevalence

is to sort of look at long-stay residence with off-label use of an antipsychotic. And the exclusions on both of course are people with a diagnosis of bipolar or schizophrenia because that is sort of by definition considered appropriate.

To AHCA, who is not, as you know, (unintelligible), they have in their exclusion schizophrenia, turrets and Huntington's Chorea. So we have to address that, but while we're addressing it, while we're thinking about it, we need to simply define our terms and make sure we know what we're doing when we're doing quality improvement initiatives in any of the homes.

So pick a measure, pick a target, focus on a process, setup a plan and do a study (act) and that is a way to, I think, begin. Now let me give you a preview of coming attractions because I have a couple of questions here in my chat room and I want to get back to them.

But here's what we're going to do in part two. In part two we're going to talk about how we make this shift from dementia from the outside in; frame behavior relationships with those five A's, amnesia, apraxia, (agulia) and so forth; and how we're going to move away from, without throwing it out completely, looking at dementia, these biological and psychological symptoms, as more than just symptoms. We're going to make the shift from outside in to inside out.

In the current model, which I hope soon becomes the old model, behavior problems are seen as either a direct result of the neurobiological impairment or an indirect result of the fact that the brain is disinhibited, or the person is disinhibited, because of damage to that part of the brain and that's what causes behavior problems.

We're going to look at a new model looking at dementia from the inside out wherein we look at who a person is and that becomes as important as what he or she has. We're going to look at the statement, all behavior has meaning. These are not just symptoms of a disease, these are not just symptoms of a bad brain, they all have meaning and they are an attempt to communicate something.

This shows up like this, a person with dementia is the focus or a person with dementia. And this we focus on what a person can do being at least as important as he can't do. So who you are, not what you have; what you can do, not what you can't do; your abilities, not your inabilities and we begin to shift in this direction, strength based.

Another way that this is often asked, and this draws on the work of (Thomas Kitwood) from Great Britain, we asked the question, what does a person living with dementia need to maintain personhood with the expectation that addressing personhood needs will actually result in behaviors not occurring?

So we really want to shift away from how do we intervene? How do we get a person to stop? Rather how do we meet a person's needs and what are those needs beyond do they have a UTI and are they constipated? What are those core human needs that drive behavior?

All behavior communicates; all behavior expresses unmet core human needs. Unmet needs are what drive behavior and this we have (Jessica Cohen-Mansfield) to thank for, for building so nicely on (Mansfield)'s 1950's work. Her model tells us that the story is more complicated than the old model that I showed you and this is what we're going to take up in part two.

To keep you busy until we meet again here are some resources I call to your attention. There is no lack of resources on the Internet. I've looked at lots of them to get you started. These are the ones that I would start with.

The surveyor training, CMS, from last March is on there. I think that's worth looking at. I would start with the AHCA Web site, which has lots of slide decks, which would be very helpful to your endeavor.

I want to thank you for your kind attention and I'm going to now go back to the beginning in the two minutes I have to answer a question from one of the participants who wants to hear a little bit more about reversible dementia and delirium. And that's why I'm going back here as quickly as I can, whoops too quickly.

Okay delirium, as you know, is identified as an acute alteration of mental status characterized mostly by inattention, extremely disorganized thinking and sometimes accompanied by physical agitation and hallucinations. It is by definition of sudden onset and the sudden acute onset.

We are all taught, whether you have a healthcare background or not, we are all taught delirium by its nature is either self-remitting or it kills you and that it is transient and temporary. That is true for everybody except really old people or people with a pre-existing dementia.

What happens there is that you get one of your usual causes of delirium, which is drugs, drugs, drugs, drugs, drugs, adverse drug reaction is always the first thing to look at; electrolyte imbalance is another thing that is common; infections are common; and there's sort of a whole checklist of medical causes, if you will, of this acute sudden markedly fluctuating alteration in mental status.

That is in contrast to reversible dementia, which tends to have, like irreversible dementia, much more self-acute onset, much slower, much more slowly progressive, certainly true in the case of depression and in the case of adverse drug reaction that builds over time.

The most famous example, I think, is a common over-the-counter drug like Benadryl where it's found to be responsible for a lot of misdiagnosis of dementia. About 20 years ago a great study, that was done about 20 years ago, to alert people to the problems with, particularly anti-cold and (unintelligible) medications, which by their nature cause cognitive impairment.

Reversible dementia due to depression used to be called pseudodementia, but because there's really nothing pseudo about the syndrome caused by depression I think that that's fuzzy thinking. There's not a psudeodementia, it's a reversible dementia. And when you treat the depression the dementia goes away.

So I hope that that's useful. I see that it's 2:02 and I see a note from (Kelly) suggesting that if you have follow-up questions that you want me to address in part two please send her an e-mail and she'll make sure that I get them and I'll answer them next time.

So in the meantime I really encourage you to check out that resource page and we'll get back to work on this when we meet again. Thank you very much for your participation today.

Jackie Hairston: This is Jackie and I hope you were able to get nuggets out of the presentation by Dr. Wehry. As I said before, if you have questions that you would like her

to answer please submit them either to me, (Pam), or (Ernestine) and we will certainly, you know, get those answers for you.

Those of you that are on the WebEx there will be a short polling question, or short poll, that will come up shortly that we ask that you answer because we do use the responses from your - from you to let us know how well we're doing and also to find out if there's things that we can, additional topics, that we can possibly bring to you.

So on that note I want to thank all of you for joining the call today and (Mark) I'll turn it back over to you.

Operator: Ladies and gentlemen that does conclude the conference call for today. We thank you for your participation and ask that you please disconnect your line.

END