Kessler Institute for Rehabilitation 8th Annual Stroke Conference: Part 7 of 8 Impact of Spatial Neglect

Recorded October 2019. Listen to it here.

PEII CHEN: 00:04 [music] So if the patient actually have some voluntarily movement ability on the left side, on the affected side, help them to voluntarily move this side as often as possible--

ANNOUNCER: 00:18 Welcome to the 8th Annual Stroke Conference, Breaking Barriers: There's More to Getting Home Than Walking. In this podcast, Dr. Peii Chen of Kessler Foundation presented Impact of Spatial Neglect on Family Caregivers of Stroke Survivors. For more information about Dr. Chen, read her bio in the program notes. This conference was sponsored by Kessler Institute for Rehabilitation and was a one-day event that provided participants with an understanding of the multidisciplinary approach to rehabilitation that enables stroke survivors and their families and caregivers to rebuild their lives. Discussion will focus on communication, motivation, spatial neglect, sleep issues, bowel and bladder management, and community integration.

CHEN: 01:14 I'm a senior research scientist at Kessler Foundation. I work at Center for Stroke Rehabilitation Research. I've been working at Kessler Foundation since 2007. So I've been working with KIR for clinical research since then. So a lot of things I'm going to talk about today is actually based on the collaboration, based on the research that we do here and also at Kessler Foundation. So my disclosures, like I said, I'm employed by the Kessler Foundation, and I receive funding from New Jersey Commission on Brain Injury Research and also the National institute on Disability, Independent Living, and Rehabilitation Research. And I'm also the lead developer of two instruments that you may heard of: Kessler Foundation Neglect Assessment Process or KF-NAP and the Kessler Foundation Prism Adaptation Treatment or KF-PAT. And related to KF-PAT, there is a patent pending on it. And so even though I'm not going to talk about KF-NAP, KF-PAT, but you may heard of it, and these are actually-- in the foundation, we consider them as product. So if you want to use them, purchase anything about it, the contact person is actually me but-- I'm basically a saleswoman in that regard. But I do not receive any financial bonuses, any compensation from doing it. So please feel free to contact me if you need information related to KF-NAP, KF-PAT. And also, I'm the content creator for two websites. I'm going to show you one of them today. So if you go on this website, you will see this. I'm going to play this later, soon.

CHEN: 02:50 This is a PSA that Kessler Foundation created, and the architecture of the website actually is here. Rob is here, our director of communication. And so if you go on this website, we created three specific pages. One is for stroke survivors. One is for family caregivers. And the last one is for professionals like you or researchers. And so the difference between the three pages is we introduce spatial neglect to three different stakeholders choosing the language that's friendly for them to understand what spatial neglect is. And this PSA air since May this year. If you haven't seen it, you're going to watch it with me today.

S3: 03:38 A stroke can be easy to detect. A loved one can't speak. Perhaps they can't move. But there is another sign of a stroke that many of us can't see. It's called spatial neglect, and it can occur during or after a stroke causing distorted visual movements. Fortunately, there is a solution by using optical prism technology during
I am not going to talk about prism adaptation today, just so you know. Today's topic is the impact of spatial neglect on family caregivers. My lecture today is to understand the impact of spatial neglect on stroke survivors, to learn the impact of spatial neglect on stroke survivors' family caregivers, and to discuss how stroke care professionals can help prepare family caregivers for caring for a patient with spatial neglect. So you probably know these stats already. Every year, more than 795,000 Americans have a stroke. And more than 80% of them survive it, which is good, right? They don't die out of it, but that means we have a lot of stroke survivors. And as all of you know, stroke, it's not just that moment. The recovery can take years. Sometimes, for some patients, it take their lifetime to recover from stroke. An estimate of 7.2 million American adults are stroke survivors. This number is likely to increase because our population is aging and also because stroke survival rate is improving. And the number down here, it's a worldwide number. So worldwide, there are 80 million stroke survivors, and 50 million of them are permanently disabled. So we have a huge population that we're serving here.

So I just mentioned the regaining functional independence after stroke can take years. And also, what is functional independence? From clinician perspective, we have our standardized scales. For patients and their family members, their functionally independence could be very different from patient to patient, right? So some patient, they struggle a lot how to return to their normal self, or they have just to adjust with the new life. And one factor prolonging this recovery very significantly is spatial neglect, okay? And before I tell you what it is, I'm going to tell you more numbers. So this number, this stats is actually coming from Kessler Institute. That's we did a study with KIR. We found that this syndrome or disorder, spatial neglect, occurs in 50% of stroke patients in rehabilitation hospital setting.

So what is spatial neglect? It's a syndrome of impaired spatial attention. So most stroke patients, they have unilateral brain damage. So stroke occur in the brain, by the way. A lot of family members or patient themselves, they actually do not know about this. I believe doctor told them, but they're just not paying that much attention at that stage. However, as you know, stroke affects brain and-- sorry. I'm doing this gesture in the air. So for example, in this case that I'm going to-- this example I'm going to give you today is all based on patient who have right-brain stroke, and they're neglecting the space opposite to the damage. Why is that? As you know, after right-brain stroke, patients' left side, their left body is weaker, right? After left-brain stroke, the right side is weaker. Similarly, attention is the same thing. After right-brain stroke, your attention toward the other side is weaker. If it the stroke happened on the left side, your attention to the right side is weaker. Okay. So these examples are based on different-- I'm going to show many examples. These are examples I collected from patients who have right-brain stroke, and they show left-sided neglect.

So for example, here, this is a copy task. This is the model that patient is supposed to copy down on the page, just on a regular letter-size paper. And the patient is paying a lot of attention on the right side, neglecting the left side. So as you see, these two
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trees are drawn here, half of a house, half of plant. Okay. And in this particular example, the patient showed two types of neglect. Most neglect that we’re seeing clinically are so called body-based. They neglect the space, left side of the space related to their body. But about 40% of the patient, they also neglect left side of each object. So for example, this tree is on the so called good side, on the right side. But the left side of the tree is missing. The left side of this house-- the left side of this plant is missing. So if you want to translate into daily lives, just imagine like some patient, they only eat half of a plate on the table and only pay attention to the right side of each object.

CHEN: 08:44

Another example, this is so called target cancellations. This task is actually done here on this location, a part of their screening for neglect. And so the task is we print this page out, and we give it to patient. They look around, and we want them to cross out all the small stars. So there are big stars, small star, and letters. And so you can see this patient paying a lot of attention on the right side, neglecting the left side almost entirely. In this example, I gave the patient this paragraph printed on a piece of paper, and I hold exact same paper in front of me. And I ask him, "Can you read this paragraph?" And so on my end, I just underlined the words that he read. So again, he's not reading anything on the left side. He read words on the right side.

CHEN: 09:41

In this example, I want to show you spatial neglect is-- it can be disabling a lot of daily task, especially reading. We read almost every day, but we don't tell people what we read. So in this case, if I didn't do that or ask him, he was, "Oh, I finished reading," and I will believe him, right? The funny thing-- not funny. The interesting thing is he said, "This is an interesting story." So actually this happened after I-- well, I'm a researcher, so I have to consent patient into my study. After he did this, I'm, "Oh, let's do the consent again." Because during the consent, he read the form. I didn't know what he read, right? So at this time, I have to read word by word with this person.

CHEN: 10:27

Here are more examples. So in that case, that's a very severe case of a patient who have neglect. This person also have right-brain stroke. And we cannot do any test with her but her position-- this is her default resting state. She was just sitting there doing nothing. But her center is all the way to the right, so she sit leaning all the way to the right, okay? And then leaning this way, and her eyes is focusing on the right side. In this example, there's no-- this is actually classic. I stopped this man in the hallway, and I said, "I have to take a picture of you." We call this hanging glasses syndrome. So I saw some of you wearing glasses. I wear glasses too. Now, I'm wearing contact lenses. In the morning, when you just woke up, right, you fumble. You find your glasses. You put it on. No problem. You don't need vision to put on glasses because you know how big your face is. You know how big your glasses is. You know where your nose, where your ears are. Most people should be able to do that. And in this case, this person is neglecting the left side of his own body, so the left side of the glasses is hanging. And also why I take this picture is because - maybe it's not very clear on the picture - he only shaved the right side of his face that morning. So this is very, I will say, common in male patients. In female patients, sometimes you'll see them-- they only put makeup on on the right side. And these are very striking because
when they do this task, they actually do it in front of mirror. They're looking at themselves, okay?

CHEN: 12:07 So what I want to emphasize is-- maybe some of you heard of spatial neglect or different names of it, visual spatial neglect, hemispatial neglect, and some of you may think of it as a visual problem. It's actually not a visual problem. It's an attention problem affecting visual function. So the definition of spatial neglect is it's a disorder of spatial attention. It affects spatial perception. It affects visual perception, affects auditory perception, tactile perception, proprioception. It also affects representation. So if you test their spatial memory, ask them, "Can you show me--? On a blank map of America, show me where California is." They will point on east coast side. Okay. Or their mental imagery, the ability to manipulate images in their head is damaged.

CHEN: 13:03 And lastly, actually I think this most important one is [on that?] you cannot see-- you can see a lot of neglect symptoms in motor-control-related functions. And that's highly related to stroke rehabilitation, especially they lost ability to initiate movement toward the neglected side. I saw so many patient-- they only make right turn. I actually hear they will play a song from Beyonce. Some of you know there is a lyric about, I think, to the left, to the left. And also mobility, a lot of them, they're able to walk, but they cannot walk safely because they will veer. So for example, if I'm a patient with neglect, I may just slowly walk toward this side. And a lot of them, because of this - they're not paying attention on their left side - they bump into things. And that's a safety hazard.

CHEN: 13:59 So these are - what I just showed you - the symptoms and definition. Any questions? Okay. So now, here it's a cartoon of a brain. I want to tell you why after right-brain stroke, you neglecting the left; after left-brain stroke, you may neglect the right. So we all have two hemispheres of the brain, okay? And this is the network of attention. And the two hemispheres are in balance in healthy people; in balance in terms of they're inhibiting each other all the time. In this case, the right side is damaged so-- the right side is damaged. So now, the left side is strong and inhibiting it, right? Because it's so strong that it bias patient's attention all the way to the opposite side, to the right. So they're neglecting the left, okay?

CHEN: 15:03 And here is an example, recent-- well, not really recently. It's published in, I think, 2014. So basically, what it's trying to say is-- a lot of you probably read about neglect and think of it as a cortical problem or a parietal-- parietal lobe is around here. This is occipital, parietal, frontal, temporal-- it's a parietal problem. But a lot of literature and research have shown it's a network problem. Basically, anywhere it's damaged, this person may demonstrate spatial neglect. And also, it's not a cortical problem. It's actually a network problem. Network means connection. So the white matter fiber actually is very important. For someone who had lesion involving any of this white matter tracts connecting the back of the head to the front of the head, even if the lesion is very tiny, this person will have spatial neglect for a long time. It's very hard to treat.

CHEN: 15:58 Here is an example how I do the study to look at patient's lesion in their brain-- we collect patient's clinical scan from acute hospitals. It could be CT. It could be MRI. But different machine parameter, it's impossible to just compile all of them to make a
comparison. And also, everybody have different size of the head, different shape of the brain. So the way to make this comparison is to look at the-- to read the CT scan or MRI scan and literally draw on a computer patient's lesion on a template, okay? So that's how we make comparison across different patients. So the content of the study doesn't matter, but I want to show-- these are 12 different patient who have spatial neglect. All of them show spatial neglect behaviorally. But as you can see, the lesion can be large, can be tiny, could be cortical, could be subcortical. So it's unpredictable, okay? Just based on their radiology scan. So if you just show me a CT scan and ask me, "What do you think? Do you think the patient may have neglect?" Test them. I cannot say it for sure, okay? Because just remember, it is a network problem, not a focal problem.

CHEN: 17:19 Okay. All right. I think everyone is nodding, not really falling asleep yet. Okay. Great. So impact of spatial neglect. So these are based on the study that I did with the KIR staff. Consistent with the literature since 1980s, we found patients who have spatial neglect-- they stay in hospital longer, prolonged hospitalization. For patient who have spatial neglect-- stroke patients here, they stay 10 days longer than stroke patient who do not have spatial neglect. For TBI patients, 5 days longer. That means more cost. That also means they receive more rehab, so you expect they may get better eventually. However, that's not the case. They actually still have poor outcome compared to patient who do not have spatial neglect. And they have higher risk of in-hospital falls. Like I said, a lot of them, they may eventually gain ability to walk. But that actually means that they're more likely to fall because they think they're independent.

CHEN: 18:24 One thing about neglect is they do not know they have neglect. Otherwise, they will not neglect. So the key is because-- for example, for a patient who have left neglect, this is their world. This part doesn't exist to them. So for them, it's normal. This is their world. When you say, "Look to the left," they may look here. They don't go past mid-line. This is their left. So it is actually very hard to treat them if they do not-- if their self-awareness is very low. That means it's hard to treat them using strategy, right? You have to do other ways, first, to improve their self-awareness and then slowly help them to understand they have this problem and then want them to engage in the therapy, and hopefully, they will learn. So it's a difficult problem. Because of all of this, they're less likely to go home.

CHEN: 19:21 Okay. I've said that. So later, I did a study published two years ago. I worked with family members of stroke patients. I'm going to show you some data here. So I worked with two groups of family caregivers. Basically, I asked them, "Just give me an estimation, how much time did you spend with the patient doing caregiver activities?" Well, of course, during the survey, I don't use that term. I ask them, "How much time did you do last week for housekeeping, arranged transportation, prepare meals, help them get dressed, go to the bathroom, doing medication management, finance, everything?" And then they just tell what they've done, how much time they- - they give me an estimate. And this is estimation on average. It's 1.6 hours per day for a week. And then I ask them, "What about just general supervision? Just keep an eye on the patient, you're not doing anything particular but stay in the same room watching them." It's about 5.5 hours per day. And this data is consistent to the
literature because you may know stroke caregiver literature is huge. A lot of you already identified the problem, their burden and stress in this population.

CHEN: 20:38 I asked the same question to family caregivers of stroke patients who have neglect. As you can see, the number is much higher. They spend 4 hours a day doing care and assistance related to activities and 17 hours a day just supervising patients. That means all waking hours. You have to sleep for 7 or 8 hours. So it's really, really demanding. And because of this data, I have been trying to design new studies, first, to assess what is supervision exactly. What do you do? What did they do? Is it very stressful or very burdensome, and how can we help?

CHEN: 21:23 Just to make this case, I want to tell you a story of this couple, Mr. and Ms. G. So this couple, actually the patient is the Mr. G, and the reading example that I gave is from him. I worked with them for almost a year for the study. And at that time, he was five year post stroke. He still have very severe neglect, and his wife said, "Yes. People told them that he has neglect but no one--" well, she said no one told them how to address it. And then they just believe he's going to be like this the rest of his life. And it's kind of depressing. And that is one of the reason that I want to work with them. And the first day I met them, they were late. And Ms. G, the caregiver, apologized when I met them. They were late about 30 minutes. She said just when they were about to leave the house, she found out he only shaved the right side of his face. So they have to go back in and redo it again. And Mr. G has very strong personality. He refused to get help from his wife. So he just have to do it again. And so they were late. And they come in, and they do the consent. And then I do this. And I realize, "Oh, we have to re-consent because apparently he didn't read the whole page."

CHEN: 22:50 The thing is, at that time, he appear highly functioning. He walked with a cane, not even a walker. He can walk. And then he use his right hand, using the cane. He sometimes will move his left arm and then-- but it's not often. But according to his wife, he has full range of motion. He's just not using the left side as often as most people would like him to do. So then I start working with them almost biweekly. I go to their house, and usually I stay in their kitchen because they have a big dining table, and I do survey and different paper-pencil test with the patient. And usually during the session, the wife will stay in the living room.

CHEN: 23:33 So I've been there many, many times, and I witnessed one incident that's quite dramatic for me. So every time when I arrive, his wife will prepare coffee for both of us. And usually in the middle of session, Mr. G will stand up and say he's going to warm his coffee because it's not warm enough. He will just turn around because the microwave is behind him, and he will open the microwave and put it in 15 seconds, and then we continue the session. And that day, he did exact same thing. I was sitting at the tiny table and minding my own business. And 15 seconds later, the microwave beeped. He opened the microwave, and the next thing I know he's yelling at his wife--yelling to the living room direction saying, "Where is my coffee?" And the wife rushed in, and I looked up, and we both realized that the mug basically turned in the microwave and turned to the left side. When he opened it, it didn't occur to him just to look-- because there's only 15 seconds. No one come into the kitchen during that time. But the first thing he think to do is to ask for his wife's help. And I would say that
is a quite dramatic time for me because even if I was there, his wife has to be in the same house too.

CHEN: 24:57 And later, his wife told me about an incident. They did a road trip to Maryland to visit their daughter, and they stopped at a resting area, go to the bathroom. He accidentally walked into ladies' room because he only read men on that sign. And they were both super embarrassed. And so from that time on, his wife have to accompany him all the time to make sure that he go to the correct bathroom and come back to where they should be. So yeah. So it is very stressful for family caregivers, especially for them-- even though they were told the patient have neglect, but they don't understand what that really means in daily life. And then some people- "Oh, he must have dementia." But it's not. It's spatial neglect. And it's actually treatable. And it's just really unfortunate. So I really want to advocate for assessing and treating spatial neglect.

CHEN: 25:57 Okay. That's just one case. And in this study, we have 40 caregivers involved. And so other than asking them to estimate how much time they spend doing all those task, we also use this self-report scale, ask them what they feel about their different areas of burden. So in this graph, the dark parts are caregivers of patient who have spatial neglect. The lighter parts are caregivers of patient who do not have neglect. And there are five areas assessed. These three are almost the same. But these two, caregivers of patient who have neglect, they report higher burden than caregivers of patient without neglect. So I'm going to highlight those two areas. Basically, they report higher or more burden in general strength. So I'm going to read some questions out of this area. So for example, "Do you feel tired or worn out? Do you feel tied down? Are you mentally tired from taking care of the patient?" Okay. And isolation, this area, there are three questions. One is, "Do you avoid inviting friends home? Has your social life lessened?"

CHEN: 27:16 So in the same couple, this remind me-- so Mr. G, he was actually a writer, and he love French movies. He has so many old French movies. But after stroke, he said he couldn’t watch them anymore because he couldn’t read the caption. He didn’t say that, but that's what I assume. And he prefer to stay home, but his wife told me she actually prefer to go to see new movies so that she can get out of the house. And I hope, in my future study, I can actually assess this burden even more specifically.

CHEN: 27:56 So here are some potential solutions that I suggest to family caregivers which you may be able to do in your clinical practice. So I hope you can communicate about spatial neglect through concrete examples using functional outcome measures. Rather than showing family caregivers a drawing performance, that's not very helpful because patient, they don't usually draw in their daily life actually. So that's what this- the instrument that we developed called KF-NAP-- it's very helpful because usually OT will go to patient's room and observe patient in daily activities like, for example, watch them to finish a meal or watch them how to clean their face or shave. And then they can present the result to the family members and show them concrete example what does spatial neglect look like in daily life. And that will help this communication. Rather than telling family members, "Oh, it's spatial attention problem." They can see...
just they don't attend. It's very hard for anyone to understand that statement. So provide concrete examples always help.

CHEN: 29:04

And integrate spatial neglect management and relate the safety precautions into systematic protocol of family training. I know there is no standardized family training protocol. It's really based on your practice, your scope of practice or your discipline, you may have different kind of training. But spatial neglect is very fundamental and essential to almost all activities that the patient do-- you have any interaction with the environment with people. So you can try to integrate this. Especially some patient, they have very low self-awareness. It's harder for them to learn strategy. Even if they learn strategy, they may not remember the cue. Okay. So you need to integrate all this management into your family training.

CHEN: 29:47

And of course, to share evidence-based approach that may improve patient's spatial attention toward neglected side. So I'm going to share what so called evidence-based approach-- there are evidence-based approach to treat spatial neglect. And recently, American Heart Association, American Stroke Association, they published this guideline for stroke rehabilitation in adults. So this colorful chart is just the way, the system they use-- how to evaluate different studies focusing on different type of symptoms after stroke. For spatial neglect, they recommended seven different treatment options. So there are options, okay? And because today's lecture is focusing on family caregivers, I'm going to recommend things that family caregivers can do safely, okay, and of course, you can demonstrate it to family caregivers first and then to facilitate them how to do it with the patient. Just full disclosure, I'm not going to talk about prism adaptation and virtual realities because family caregivers, they cannot do these two.

CHEN: 30:57

So the others, visual scanning training, some of you may know about this. If the patient is able to learn strategy, you can teach visual search, scanning to start and anchor on the neglect side. Let's say if patient have left neglect, help the patient find the edge of the left side, either the table or piece of paper or the beginning of the paragraph. So some strategy is to put a colorful object on the left side. And then some patient, they may not be able to find the edge. So you literally just take their hand and trace all the way. Patient can do that, okay? They just trace. And then after, of course, multiple practice, they will learn. They have to do this first and then stay there, and they can start scanning. Okay. So for example, I saw a female patient. She put her index finger nail polish in red to remind herself she always have to do this. Okay.

CHEN: 31:58

Next one, the optokinetic stimulation. This is an eye movement exercise. It's an exercise turning eyeballs from the good side-- so for example, from the right side to the left side. So you can use your finger or any object. Ask patient to look in front of you and then don't move their head, just move from the good side to the bad side. Just keep practicing this eye movement to stimulate the neuroplasticity and paying attention to the left side. So this is actually not a strategy learning. Really it's something that someone has to initiate this and then really practice a lot.

CHEN: 32:42

Okay. Limb activation, so this term, the term activation meaning activate the brain, okay? So like we just established, right side of the brain control the left side of the
body, right? So if the patient actually have some voluntary movement ability on the left side, on the affected side, help them to voluntarily move this side as often as possible rather than just-- I want you to move. You have to find some strategy to help them to keep moving on this side because the more they move, the more this brain is activated; this side of the circ is activated. And attention network is highly dominated over here. So it will help the structure or reorganization of the neurons on the affected hemisphere. So this is why it's called limb activation.

CHEN: 33:35 So like here, I'm going to read it, "If the patient is able to move the affected arm, use it to perform reaching task toward neglected side." So the patient I just show you-- she have very severe leaning posture problem. She couldn't really follow commands. So it's very hard for her to participate in therapy. So her husband asked me, "How can he do to help?" And I said, "Just ask her to point your nose or touch your nose." So start from the bad side. See if she can do it, if she can touch your nose. And if she can, then sit to the left side. See if she can do that. And then yeah. They practiced that. Every time when the husband visit her in hospital, they can practice that. This is a good practice because it's practice outside therapy session. As you know, rehabilitation is all about repetition. You want the patient to do this again, again, again.

CHEN: 34:33 Last one, neck vibration, literally meaning vibrating the neck. So you can use massagers or different-- even without the device, you can just rub the back of the neck on the neglected side. So really it's massage the back of the neck on the neglected side, just read it. So it's very simple and a caregiver can do. And then especially if they're spouses, it's something that they can do. Okay. Any questions? Yes.

AUDIENCE: 35:05 The neck vibration, is it during functional activities, or?

CHEN: 35:08 You can do that too. Yes.

AUDIENCE: 35:10 So is it just like a reminder, or is that actually--?

CHEN: 35:13 It's a sensory reminder. Yes.

AUDIENCE: 35:15 Is it actually helping the neuroplasticity or improving that--?

CHEN: 35:19 There is actually evidence showing that. Yes. Because here, it's very close to vestibular system. That's why it's the back of the neck rather the back of some parts. Yeah. It's here. Okay. All right. So the takeaway message, spatial neglect is a syndrome caused by impaired attention network. That's something I want to really instill in your brain. It's not a visual problem. It's a disorder that affect vision, okay, and affects other things: affect motor control, affect your tactile sensation too. Spatial neglect affects multiple perceptual, cognitive and motor functions. Family training should involve the demonstration of neglect symptoms in daily activities and include practical tips for sensory cueing and safety precautions.

CHEN: 36:12 So lastly, I want to thank many people because I cannot do all this by myself. Dr. Barrett, she is still currently my supervisor, but in a week, she is moving to Georgia. She is going to be part of Emory System. Dr. Mooyeon Oh-Park, she was actually also
here as attending physician. Now, she’s the medical officer of Burke Rehab. Kimberly Hreha, she was here too. I know [when?] I left-- she was an OT here forever-- not forever, for eight or nine years, and we always worked together. Even now, we still work together. And then she got her doctoral degree, and then we’re still collaborating. And Jenny Masmela is a research coordinator in my research center, and without her, I cannot do a lot of things. So because yesterday I prepared business cards, but I run out of it. So if you want to contact me, please email me. I put my email here. If you cannot see, it’s P, the initial of my first name, pchen, my last name, at KesslerFoundation, one word, dot org. So if you have any questions, you can ask me during the panel session or email me. Any question is welcome. [applause]