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Needs and expectations of elderly breast cancer patients

Ms Oldenmenger: Thank you very much for this invitation. My name is Wendy Oldenmenger. I'm a nurse researcher and work as an Assistant Professor at the Erasmus MC Cancer Institute, and as a Senior Lecturer at the University of Applied Science in Rotterdam, the Netherlands. Besides, I'm a member of the Executive Board of the European Oncology Nursing Society. And in that position, I'm invited to give this presentation today about the nurses' perspective. Now, it's been estimated that by 2035, 2/3 of all new cancers globally will be in older adults, with the fastest increases in the less developed parts of the world. The older adult population is the most heterogeneous in terms of health and functional status compared to all other age groups. But what are elderly people? It's not clear what the definition of elderly is. Is that 65 years and older? 70, or over 80 years? And this differs regardless [Audio Not Clear] of published publication. Nurses provide key contributions to the care for older adults with cancer by supporting treatment decision-making processes, providing education to older adults and their caregivers, and addressing and managing health and wellbeing before, during and after treatment. To understand the current challenges in nursing practice, a solution proposed by nurses, the European Oncology Nursing Society, the Canadian Association of Nursing in Oncology, and the International Society of Geriatric Oncology conducted a survey with nurses working in the care for older adults, and mainly, breast cancer nurses. The proportion of older adults aged 70 years and over where these nurses involved in this study managed for per week ranged from 2 to 100% with a mean of 15%. So, this patient group is a significant part of the nurses' jobs. Now, information of this survey is organized in three topics. What are the problems we need to solve as nurses? What ethical concerns have nurses encountered? And what can cancer nurses do to improve the care for older adults with cancer? And the first topic is the challenges in caring for elderly patients with breast cancer. Well, what are the problem in caring for elderly patients with breast cancer? And nurses describe the problems that need to be solved in four areas. First, the challenges related to the aging process in the patients, including dealing with comorbidities, cognitive problems, lack of social support, slower information processing, and changes in sensory function. And some of the challenges are practical challenges related to the clinical space to work in, and to the ways information was offered to the older adults. And the second area are the challenges related to the system, including the lack of time to meet and assess the needs of older adults. Nurses described difficulty assessing services for the older patients. The third area is the lack of knowledge and awareness about the needs of older adults with cancer. Nurses reported that there is a general lack of awareness of the needs of older adults with cancer, and the need for appropriate screening and assessment for the care plan. And the last area of this concern is the lack of recognition of the nurse's role in the care for older adults with cancer. Nurses noted that the lack of clarity about who's responsible addressing the age-related issues and challenges associated with coordination of care. And this is well-illustrated by this quote of one of the nurses. She says "Treatment decisions are too much focused on technical endpoints like survival instead of quality of life or functioning loss due to treatment. I believe that when nurses are more involved in the decision-making process, and function more as a spokesman for patients, cancer treatments will be more fitted to the patient." And now the second topic, nurses describe ethical concerns in their daily practice in three areas.

First, were concerns about over- and under-treatment of older adults with cancer. These concerns very important by almost all nurses. Nurses reported concerns about the intensity of the treatment provided to older adults, as well as who received the treatment, and whether these individuals had the capacity to give truly informed consent. Besides, nurses also voiced concerns about access due to the financial concerns of travel distances to treatment. And the second area of the ethical concerns are concerns about the timing of advanced care planning and discussions about the initiation of palliative care. Nurses thought goals of care discussions, as well as advanced care clinic discussions were initiated too late in the disease trajectory. And the last area here are the conflicts between patients and family treatment goals and wishes. Nurses reported ethical concerns about the situation that older adults who are cognitively intact and able to participate in a treatment decision-making process, yet having family members try to make the treatment decisions for them. And this is illustrated by quote of one of the nurses saying that "Advanced care plans are regularly not on the cancer chart," or that "The system is designed to treat. Moving away from aggressive treatment is difficult to integrate for many clinicians, but may best align with patient's goals." I'm coming here to the third topic of the survey. What can cancer nurses do to improve care for older adults with cancer? First, being advocate for the patient with a proactive practice. A key-practice is ensuring the care team is aware of the needs of the older adults. They identified a need to be proactive advocates for high-quality care for the older adult population. And participating in geriatric screening and geriatric assessments is the second area. Nurses reported cancer nurses have the knowledge and ability to conduct geriatric screening and geriatric assessments. And completing these tools are a key-practice element. And the last area here is promoting education, including education for A, patient and caregivers about the treatments and care plan; B, other team members about patient visions and goals; and lastly, educating themselves about geriatric oncology screening and assessments. And this is well-illustrated by the quote one of those nurses gave. "I think that cancer nurses should be at the forefront of assessing older patients and have a voice in guiding decisions. I think nurses are sometimes in a subordinate role. We spend the most time with patients and family, and can uncover functional or cognitive deficits that most oncologists maybe may not." Now, a first action to gain more attention for the specialized care for older adults with cancer is a global supported position statement that was written to help nurses to advocate for the needs of older adults with cancer, and to provide high-quality care for the specific cancer population. And next to the three mentioned societies, this position statement is also supported by the Oncology Nursing Society of the United States. Now, this statement outlines the four roles of cancer nurses to advocate for specific needs of older adults with cancer, to identify educational needs related to the geriatric oncology knowledge and skills required in daily practice, recognize age-related issues, and lastly, support older adults during and after the cancer treatments. And to see the more in-depth age statements, and more importantly, how to implement these statements in daily practice, I advise you to read the full article. In conclusion, there is a need to advocate for the resources and models of care to meet the needs of older adults with cancer, while also supporting education for nurses to become more knowledgeable in geriatric oncology nursing care, both in general and specific for elderly patients with breast cancer. And this all should be implemented in a general nursing curricula. Our next step is to work together on developing education resources for all nurses caring for older adults with cancer, to support development in geriatric oncology nursing. And why is it possible that there is a global recognition for specialized care for adolescents and young adults and not for elderly with cancer, and especially, in breast cancer? In all kinds of advertisements, we see young women, but the main group who get breast cancer are older women. Both groups have their own specific needs. So, maybe, we need to make geriatrics more sexy? Thank you.

Dr Travado: Hello, everyone. I am Luzia Travado, Clinical Health Psychologist specialized in psycho-oncology, based in Lisbon, Portugal, and working in this beautiful facility called the Champalimaud Clinical Center of the Champalimaud Foundation. I have also the privilege to or honored to be the President Emeritus of the International Psycho-oncology Society. And I'm happy to speak to you today about the needs and expectations of elderly breast cancer patients from the psychological perspective. And I will address both

early and advanced cancer patients. So, when we are talking about elderly patients, it's not exactly how old you are, but how you are old. All of us know elderly patients, and we know that they look so different. We can have a happy, functional couple enjoying their recreational activities. Or we can have women that are not so happy, and feel somewhat loss or staying mostly at home. Or we can have patients that face limitations. Or we can have women also still striving for their physical shape and trying to look as best as possible. So, really when we are facing an older patient, they can be very different. And it's quite important that we really understand who is the patient that we have in front of us. Mostly, the characteristics tell us that there is a higher probability of occurrence of health problems, disabilities, chronical diseases, multi-morbidity, also, organically-related mental and neurological disorders, and a lot of stress factors; so, mainly the presence of physical illnesses and these multiple chronic conditions which impose limitations on the independent life, diminish their social participation, their quality of life, introduce disabilities in the activities of daily living, also, the cognitive impairment with memory loss and others issues related with cognition, the loss of loved ones, the family and friends, loneliness, and sometimes moving to a nursing home. So, there is a complexity of symptoms and needs when we address this population that is important to keep in mind. So, for a better treatment planning, we need to assess different areas, so, not only the physical functional status, but also mental health, including psychological wellbeing, these multiple chronic conditions, and medications the patients are taking, also, which are the factors that impose stress on our patients, their social situation, their cognitive function, their quality of life, and also patient's needs and treatment preferences, so as to better provide a treatment plan that is tailored to our individual patient. We also know that the main mental health problems of older persons are cognitive alterations, emotional problems, psychological morbidity, particularly depression, as I mentioned, loneliness, feelings of unworthiness, hopelessness, withdrawal and sometimes, suicidal impulses or attempts, also, anxiety disorders and other behavioral alterations, such as agitation, irritability, sleep alterations and others. So, a lot of issues that we need to understand their impact and what assess if our patient, the person who is in front of us has any of these so that we can properly address those issues. The studies that have shown and studied distress prevalence in elderly patients have shown that elderly patients have a high prevalence of distress. In this study, almost a half of percent of the patients had significant levels of distress. And the most common problems were worries, depression, pain, economical problems, and fear. It seems that married participants and having higher education and higher monthly income protects from psychological distress because these patients have lower distress than single patients with lower education and lower monthly incomes. So, the authors conclude that psychological distress is prevalent among elderly patients with cancer. And this needs to be addressed by the multidisciplinary team and integrated psychosocial care into their treatment plan. Another study has gone through how anxiety and depression impact on survival, and if they are prognostic variables. They have studied incredible, large cohort of patients in Canada, more than 26,000. And they have found out that, indeed, anxiety and depression are independent prognostic variables which negatively impact survival. You can see here that patients who had no anxiety and those who did not have significantly statistically more survival time. And for the depression as well, patients had fewer survival months than those which did not have depression. This is an issue that requires psychological support. So, the authors conclude that indeed, geriatric oncological patients should receive psychological support and follow-up to better improve and optimize survival. And we have known for long what are the risk factors for depression. We know that social deprivation, that lower, decrease of social activities, recreational activities, the functional impairments, comorbidities, the loss of a partner, sleep disturbances, previous depressive illness, being a female, having lost some cognitive functioning, especially memory, having previous anxiety disorder, and also, factors related with the disease like the cancer site, the stage, the symptom severity and the treatment and its specific side effects. They all can produce factors for development of depression in our patients, which we need to be paying attention to. But there are also, and this is the good news, there are very good evidence, nowadays evidence-based interventions that have proven efficiency in reducing the psychological suffering of our patients. Those are the most commonly used interventions, but there are also specific interventions for elderly patients that have also proven its benefits in reducing depression, anxiety, demoralization and

loneliness among adults, and also, some other like this, other one, community coping and communication, support for older patients, which is a supportive intervention that can be conducted by telephone, email or clinical visit according to patient preference, can be conducted by trained nurses, and can be conducted until death. And the caregivers can also continue during bereavement. So, we can really nowadays provide psychological interventions that have helped our patients reduce their psychological suffering, then therefore, optimizing their survival and their quality of life. So, I want to tell you about two cases, one of an elderly breast cancer patient, and another of metastatic breast cancer. So, here, the breast cancer is a case of my friend's mother. And she was diagnosed with breast cancer with these characteristics. She was a 75-year-old woman, beautiful, well-cared and well-married. She has had already done surgery and radiation, and was beginning her own hormone therapy, but was prescribed chemotherapy. So, chemotherapy, she was very afraid and didn't want to take chemotherapy. She stated that the most precious thing for her was to keep her physical and emotional stability so as to continue to enjoy her good quality of life with her husband. And she was afraid that while making the chemotherapy, while making her lose her hair, it would also make her lose her joy and draw her into a cascade of loss of control. So, she asked for a second opinion. The multidisciplinary team discussed the pros and cons of giving her chemotherapy, but there was no agreement as whether she was... of the complete benefits of giving her chemotherapy. So, the patient was informed about the percentage of benefit and the pros and cons. And since there was a small percentage, only a small percentage of benefits, she decided not to take it. And this was supported by her oncologist. She's now 80 years-old, very well, continuing with her hormone therapy, which she will continue for 10 years, and still enjoying life with her husband. The other case of, let's call her Patricia, she was diagnosed with a lobular invasive breast carcinoma at the age of 49. She then had a local recurrence treated at the age of 60, and then, a metastatic breast cancer recurrence at the age of 68 with mets in the bone. She had already undergone five lines of treatment with the regression of liver metastasis and stability of bone mets. She's an independent woman living alone, not married, no children. She values her retirement and to enjoy physical and recreational and social activities. Her quality of life is everything to her. So, she negotiates fiercely treatment with her oncologist, according to the side effects, limitations they may produce. She also is very keen on reducing imaging exams with radiation, which challenges her oncologist. But both have an agreement that works well for the patient, and consistently affirms the trust and confidence she has on her oncologist. Now she's 75 years. She's living well with many bone metastases, have reduced a bit her energetic activities, but still well and independent and enjoying her life. So, the issue is, which treatments for which patients? So, we need really to balance between the pros and cons of the treatment. Maybe, life extension is not so much of a priority for our patients while quality of life, yes! So, we need to balance these quite well, understand what are the patients' preferences and constraints, have a good communication as to make an informed decision. And the multidisciplinary, multi-professional team needs to also help with the symptom management, the psychosocial care, and eventually, palliative care when needed. So, treatment decisions, as we understand it, are influenced by many factors, as it's stated here, for all the conditions that the patients present. So, medical treatment needs to balance between the loss of current functioning, quality of life and possible life extension. But good communication skills to elicit patients' concerns and goals and make appropriate recommendations for treatment are of essence. And the lessons taken from these two cases is that in both cases, patients need information to make informed decisions. Quality of life is more valid than quantity. The trust in the oncologist is crucial. Good communication skills are essential. Patient-centered care to understand patient's preference and needs and understand that each patient is different and requires adjustment and flexibility on the treatment solutions, and negotiate treatment choices, sharing decision-making through good doctor-patient communication, and this balancing of cost-benefit of the treatments. So, in summary, geriatric patients are complex. We need to integrate clinical and psychosocial factors into comprehensive treatment planning. Good communication skills are essential to individual tailoring the treatment plan, according to patients' vulnerabilities, needs and preferences. And we, the healthcare professionals, have to adjust their care to patients' needs, the care we provide them, and not the opposite. It's all about them and not about us. So, thank you very much for your attention.

Prof Wright: Hello, my name's Juliet Wright. I'm a geriatrician from Brighton, in the UK, and I'm going to present my experience as a geriatrician working in a joint geriatric oncology breast cancer clinic. So, the work we do is very much underpinned by the 2009 NICE Guidance, which recommended we should treat patients with early invasive breast cancer, irrespective of their age, with surgery and the appropriate systemic therapy, rather than just endocrine therapy alone, unless there was significant comorbidity. I think this was a much-welcomed recommendation, but there was concern that the evidence for this was largely based on younger patients with fewer comorbidities. And we can see from the NABCOP Annual Report in 2018, that after the age of 70-74, there are fewer patients having surgery for their breast cancer. And you can see it's quite a sharp decline. And right away, as a geriatrician, I'm just sort of bringing to the presentation how very difficult working with age is. Because just looking at this slide, David Attenborough on the left is a fantastic example of successful aging, and a much frailer patient on the right who could be much younger. So, really using age is very problematic in decision-making. Decision-making in oncology has also been very much underpinned by performance status. Just these four, or four to five categories, just thinking about category two, performance status 2, patients spending more than half of the day up and about, able to self-care, independent, but has symptoms. That's a huge section of patients that we see which may have quite significant organ failure, which may be a risk for operative intervention for breast cancer or may not. So, I think there are challenges certainly with using agents, and certainly with using scores like performance status. Aging is normal, and normal aging I've listed many of the characteristics here. This would not necessarily concern an oncologist or a surgeon planning treatment, but clearly, does need more thinking about: weight loss, declining kidney, pulmonary, and immune function, and what does that mean? What does that mean for risk? I always give Fauja Singh as an example, as someone who quite remarkably was running marathons aged 89, and getting times of 6 hours 54 minutes, but, you know, three years later had taken a considerable amount of time off that was improving. So, really example of where age is not telling a correct story or giving an accurate picture of physiological reserve, so, helpful, I think, in terms of information about groups, but not individuals. And we know that there's a lot of conscious and unconscious bias in decision-making throughout medicine, not just in oncology. Geriatricians talk about frailty. And, you know, I've sort of referred to it as the F word there because it's a difficult term, isn't it? It does have negative connotations about health and already starts to introduce bias. And I much prefer us to think about this as robustness, or reserve and, you know, an R word. For me as a geriatrician, it's your vulnerability. It's how much of a risk state are you in, and that slightly depends what you're talking about. So, from the breast clinic that I do is, what is the risk of surgery? What would be the risk of other treatments? In general geriatrics, it can be some patient who is very frail, can have a really disproportionate change in their health, going from mobile to immobile, for example, with just a urinary tract infection. This scheme is a simplification. And again, thinking about our breast clinic, the stressor event there in red would be breast surgery, for example, which might cause falls, delirium, and onward negative health outcomes. So, in our clinic, everything above the stressor event and to the side is what we're considering. Is there something here that we can make better? Is there something that we can optimize, something that we can reverse? Or actually, does the information tell us that an active treatment is not in this patient's best interest, and that perhaps we were giving them, we would be giving them more morbidity or a poor quality of life or poor outcomes. So, really this is the sort of the fundamental schema behind the decisions that we're making. And delirium, for example, is a common presentation of frailty, both in general geriatrics, and would be a concern for a patient having an operation. And really in our clinic focusing on that risk, is it a reasonable risk, is it something that we can prevent? It would be a typical consultation. So, I like the word robustness. Frailty is well-considered in the literature. It is actually very difficult to formally define. Most of the evidence in the literature refers to the frailty phenotype in terms of reels of randomized trials. This is quite an established score, back in 2001, five criteria, and essentially, a patient is defined as robust, pre-frail or frail. It is very physically focused. So, if you're using that as a screen or as a tool in the breast clinic, you're going to miss quite a lot of comorbidities, and you're gonna miss important factors like cognition or mood. The Canadian group led by Rockwood have proposed this, you know, very well-referenced alternative model, the frailty index, which is really looking, is multidimensional.

It's looking at a number of functional deficits. So, for example, if a patient had 10 out of 40 deficits, their index, 10 over 40 would be 0.25. And this would identify them as at risk. And again, you know, this is very helpful. This is very inclusive, quite time consuming. And really when you think about the clinic, is it asking the right question? Is it picking up the patients that we need to think about with respect to breast cancer treatment or the patients that we need to intervene with? Probably, most people are familiar with the clinical frail scale from the same group. And there's quite a lot of evidence now for this in terms of negative health outcomes or associations with health outcomes in acute settings and in ITU. It was originally reported as the final part of a comprehensive assessment, rather than the start of a comprehensive assessment. It is not validated in the under 65 or those with a disability. And it's really important that it's not applied in the acute setting. It is what is the patient usually liked two weeks ago, for example. And there's many more of these scales, the Edmonton Frail Scale particularly, evidenced in surgical outpatients. So, I think the point of these scales are they are picking up patients regardless of age. It's not about age, it's about their risk. And I think in a breast clinic, you would say, well, risk for what? Is this the right way to identify people who need geriatrician input or multidisciplinary team input? And, you know, I just to underline as well, that frailty is not permanent. Using Fried, if you score 1, it is very reasonable that with input, you could become non-frail. If you're scoring 3 with directed input, perhaps, you could become pre-frail. So, whilst it is important in making sure you don't treat people who are too frail, it is a dynamic state. So, for example, someone who has been identified as at risk, who comes to our clinic, who has functional impairment, at this point, I might think, well, why? Is it because their atrial fibrillation is not treated? Is it because they have undiagnosed heart failure? Are we looking at somebody who's got early Parkinson's disease or gout or something that really is reversible? And again, it's that focused assessment really which is key. Fit for frailty, the BGS British Geriatric Society best practice guidance is, I think, a really helpful document to guide the screening and the treatment for frailty in outpatient settings. And, you know, it's simple. There's so many recommendations and so many guidelines, it's simple. And they recommend the screening, either the Prisma-7, which I've listed here, a walking speed assessment, or a timed-up-and-go assessment, which would then allow you or feed the patient into this scheme. So, the pink holistic medical review is what we're doing in our breast clinic. So, we don't use those screening tools. Particularly, I'll tell you how we screen, but it's in that holistic medical review, which takes sort of 45 minutes that the work of assessing our patients or beginning their journey to make sure that they get the correct treatment is largely done. And you can see that the entire schema is the full Comprehensive Geriatric Assessment, which may require many other healthcare professionals to support, and that can take up to sort of 2 1/2 hours. So, I always, when I'm thinking about services or how to support older people in other circumstances, we do something very similar for older people with HIV in Brighton, it's this schema which I think helps design that. So, in our clinic, we have a local need for this service. We have an elderly population. We have an academic interest, and as I've said, we've done similar in other patient groups. So, our clinic is a breast surgeon, a geriatrician, and a specialist nurse. There's the three of us. There is a parallel oncology clinic as well, which does help with speed of referrals. And so, rather than using any of those tools that I've talked about previously, our referrals are internal. It is older women, but there is no age-cutoff. And our patients have been newly diagnosed with breast cancer. The usual service has considered them unfit for surgery, or the patient is declining surgery. And we need to really unpack why that is. And we also see patients who are on primary endocrine therapy who develop disease progression. So, I've put CGA in there, but that holistic assessment is led by me. And I will focus on what is the main issue. You know, what is the main cause here? What's the main challenge for these patients' treatment? What's the main risk for their treatment? What is it that I could optimize so that we can take the next best steps? From the surgeon's perspective, having established that first part, we then join together to think about a management plan. I think with breast cancer patients, often, we have a little time because the patient will be on primary endocrine therapy. And we know that for those first two or three years, outcomes are very similar if the tumor is endocrine positive. So, there is time for optimization and to refer to the MDT. So, here we are. This is me and Professor Malcolm Reed. You can see the notes are quite thick, which probably means there's quite a bit of comorbidities. And I'm there beginning that holistic assessment, Malcolm is switching over and thinking very much from the

specialist, the specifics of the surgery. So, you know, it's a truly joint clinic. We do use the Age Gap Decision Tool for which Malcolm was involved in the body of research that supports this from Sheffield. And what this allows us to do is to have some numbers. We are comparing surgery and primary endocrine therapy with primary endocrine therapy alone in our patients. And we use some very simple data about the tumor, about comorbidities, and about activities of daily living. And this then generates an outcome. It tells us how many patients will be alive at two years, and at five years with surgery and endocrine therapy, or just endocrine therapy, so, clearly not enough on its own, it's a plan treatment, but it gives us a guide. And it is an objective measure, which allows us to add that to the holistic assessment. How do all those comorbidities combine? What can we optimize? What does the patient want? You know, and it works nicely. We've been doing it since 2015. This is just a snapshot of the first five years where we'd seen 182 patients, including 3 men, and clearly, an elderly group, average age 82, but ranging from 69 to 99. We followed the patients up. And that, as I said, is the beauty of the breast cancer clinic. And they do take quite a bit of follow-up so, we can assess how they're responding to treatment. 13% of patients who were not going to have a surgical treatment went on to have a surgical treatment. And this was successful. 10%, we changed endocrine therapy, and 35% needed medical management. So, it's clearly evidence-based in terms of decision-making. It is labor-intensive, I think, but our data around patient satisfaction is very, very strong. This is very well-received by the patients and families, carers, and also, by the specialists at BSUH so that we can provide this support to decision-making. I have rattled through, but it is not about age. It is very much about individualized care, and the Fit for Frailty framework gives us a nice strong schema, I think, for not just breast cancer, but for other cancer management moving forward. Thank you very much.

Ms Nordström: Thank you for giving patients a voice in this important webinar. My aim is to, in 15 minutes, give you some input to an older patient's expectations and needs. In general, elderly women play a major role in family life, not only for a husband or partner, but in helping children with their family/work life, and in social context for unpaid aid. Some continue working at a high age, but being older, you can have health deficiencies. There are comorbidities. And the social background could be an obstacle when coping with the burden of breast cancer diagnosis. The dialog with the treating physician or doctor is therefore crucial. We are all different, and being elderly has advantages, but also disadvantages, facing a new situation that threatens health and may have an impact, shorter or longer, on your continued life. The advantage of being elderly is that you have gathered life experience over many years, which can come in handy in a totally new situation. And you know yourself better than at a younger age. But you may also have other responsibilities and difficulties which a younger person doesn't have. Today, many women of age are much younger at heart, soul and body than only 20 years ago. That's depending on lifestyle development over many decades, but that doesn't apply to all. So, one point generally speaking is that women still have the main responsibility for family life, husbands, partners, children, and maybe, even helping out to a great extent with the grandchildren, and when retired, this could be a full-time job. To have a cancer diagnosis when older and still responsible for the daily well-being of the family may put a strain on these women that isn't always understood by the health carer. Also, these women usually do not talk about their importance for the family functions. Cancer treatment have side effects, and they seem to strike harder the older you are. Quality of life is affected, especially, chemotherapies on elderly women. And even also endocrine therapy has side effects. I believe, after talking to many patients, that the importance of exercise, sleep and good nutrition is more important the older we get to keep a balance. But to keep a healthy lifestyle is always important, but the effects are more noticeable when we're older, and also, much more difficult to keep up with. The general wellbeing and health status is getting lower in the elderly. And this could be one thing to pay attention to, especially as older women tend not to acknowledge or talk about shortcomings. Life is what happens here and now, regardless of age, but treatment should in the best of worlds, be possible to adjust to the conditions of the patient. And age is such a factor. Generally, in deciding treatments for a patient, include the patient in the process. Older patients may have other responsibilities and other different conditions, and the latter may be age-related. And being of age older means rich in life experience. This will possibly also mean that an older

patient most likely was brought up during a different time, lifespan, than the treating physician doctor. This could be an obstacle in the dialogue between the doctor and patient. Sometimes, these can almost compare to different cultures. It can be positive or less positive, but just being aware of such a difference can be important. Saying this as the most important part for a patient is actually the dialogue with the doctor, hopefully, only one per specialist function, meaning one surgeon, one oncologist, and one radiologist and so on. It's generally a new situation for a patient to be diagnosed with breast cancer or any kind of cancer, and previous experiences will help dealing with these potentially life-threatening diagnoses, but the patient in this position need to be able to talk to and trust the doctor treating physician. Being older is also knowing that your lifespan is running out or counting down, even though it's not usually said. The first meeting with the doctor is important. So, let this first meeting take a little more time. This is where the trust is built. This is important regardless of age, and also, regardless of age, really rewarding for both parties during the process, less anxiety and also compliance in treatment or treatments on the patient's part. The trust from the patients saves also time for the doctor in the long run. So, what is different when someone is older? Older women may have comorbidities that also will affect the new situation with a breast cancer diagnosis. They may have an older husband that needs a lot of help and attention. But cancer treatment can make this normally loving assistance to a burden, that will make life almost impossible during and for some time after treatment for the patient. Cancer treatments will affect an older person's lifespan different to that of a younger person. Life expectancy isn't the same when you're 30, 50 or 75. An older person's life may be more complicated and much more fulfilling on a personal level than one normally thinks when lumping older retired people together as a group. Most patients need some psychosocial attendance, but elderly may need more individualized assistance, and at least understanding of their life situations. Older patients are a heterogeneous group, which means that one patient cannot with certainty be compared to another as one may have a very good health, but the next 75-year-old patient may be very frail. The third may also have comorbidities and so on. One may be retired, but healthy and traveling the world to catch-up for lost times. The next patient at the same age span, may still be working. Yet another may even be running marathon. Then there are those maybe less healthy patients over a span from very frail, to coping but slowly, and also, those with comorbidities. As health also affects your mental status, this could be a factor. Standard treatment for certain tumor characteristics may not always be the best choice for every older patient. Lack of data is another aspect as older patients aren't usually included in clinical trials, understandable to a certain degree as data is needed from a homogenous cancer group to reassure the usability of a drug in question. But that also leaves out a multitude of questions concerning a rather large patient group when it comes to breast cancer. And as breast cancer is more common in older women, this is problematic, even if nowadays breast cancer also is going down in age groups. As a patient advocate, I would really wish academic studies would be able to address these issues. So, standard treatment isn't always the optimal solution for all the patients. And now, I don't mean from a medical viewpoint. Due to research development and studies, new diagnostic tools are available. And today, clinicians consider de-escalation, which doesn't mean less optimal treatment. It means the right treatment for the right patient, in other words, similar efficacy, but less toxicity. And being older can be a factor when deciding treatment, depending on the individual patient. Quality of life is also a factor that in an older patient's life, even in a shorter span may be of great importance. Treatment should be based on a patient's individual risk, considering tumor burden and biology, meaning that if the standard treatment is considered to have negative impact on a patient, the reason to suggest the de-escalation therapy shall be explained. When deciding a treatment, it should always be explained, and the patient should be able to ask questions. Patients need to understand risk estimations, and be involved in the decision process, especially, in relation to quality of life and side effects. If de-escalation is suggested, the patient must have an explanation. Otherwise, the patient may think she's not getting optimal treatment because of her age. Some patients have mentioned that they felt the doctor may have thought, well, she's going to die soon anyway, which of course have an impact on the trust for the doctor, as well as any suggested treatment therapy. There are less difficult and more difficult questions, but this doesn't mean they do not need to be addressed. Age matters for the dialogue with a patient. You probably don't ask a patient of 35 how long

lifespan expectancy they have, because the normal lifespan for women is around 80 years of age, but an older patient will have shorter lifespan. This is where it can be helpful to find out a little more about their present life situation. A healthy retired woman leading a full social life compared to someone with comorbidities and a frail health situation even before the breast cancer diagnosed, and a third woman somewhere in between those, but hanging in there to help with family situations, for children or spouse, these are situations that may affect the treatment options. Life expectancy may be one of those difficult topics, as well as questions in this area. And quite often, the patient may not even have confronted these issues for herself. So, getting to know a patient to some extent, through explaining and asking the questions, can be a step to address the more sensitive questions, which is why dialog is important from the first meeting with a patient. And as trust isn't built in 15 minutes, respect is also necessary to be mutual. Information both to and from the patient is of great importance as is continuity, meaning the patient meet the same doctor and have the same doctor that is responsible for each step of the treatment path. Elderly or rather older, generally speaking, do not talk about their shortcomings due to age. Having a cancer diagnosis doesn't change that. That is where the dialogue with the doctor comes in, to pick up what isn't said, which of course is difficult, which is why the knowledge of the life of elderly or older women need to be studied in general, not least from a financial viewpoint, as they contribute massively with a number of unpaid activities, not only through helping children with childcare for grandchildren, but in different areas in society. And their unpaid work has also an impact on their psychological wellbeing. And these play an important part of their daily life. Last, some important word. Age matters and life expectations and lifespan likewise, as quality of life. And the key issues in what I've said, is that life duties, despite age and culture gap between treating physician and the patient, and the patient's fear of being undertreated due to age, but most important is the dialogue with the patient to make the patient part and included in the process because it is the patient's life. Thank you very much.