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WEST VIRGINIA UNIVERSITY
CENTER FOR EXCELLENCE IN DISABILITIES
Cancer Disparities for People with Disabilities: Bridging the Gap
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>> LESLEY COTTRELL: Glad everyone is getting situated, muting your line. You are in. It's working. Thanks to everyone for being persistent and patient with us this month.

Melina, is it okay to get started? All right. So welcome to the March Grand Rounds. The sun is shining. We have a lot to look forward to, and we're starting that by switching things around a little bit, so we're at 1:00 our time, and I'm very excited, I'm glad we could work it out to have Dr. Dikaïos Sakellariou join us, and this is, as we've mentioned earlier, this is an international Grand Rounds. He's joining us from Greece, so we appreciate your time presenting to us and sharing us your experiences on the topic. Before you get started I want to give people a little bit of background about you. You're in the School of Health Care Sciences at Cardiff University and the way we found your work and we really appreciated your work, is you have a lot of literature published on this topic area as well as others so as we're going through Grand Rounds and we're having really good discussions I encourage everyone to take a look on Google Is scholar and see others and we can circulate more of Dr. Sakellariou's work. Recent book, Disability, Normalcy and the Everyday, and I read some pieces of that. I'm not completely through but it is a great read so I encourage everyone to find that on the bookshelves or eShelves.

And with that, I'll turn it over. I do appreciate again everyone joining us for March CED Grand Rounds Ability presentation. Dr. Sakellariou, I'll turn it over to you. Thank you.

>> DIKAIOS SAKELLARIOU: Thank you very much. I'm really excited to be here with all of you well tonight for me, it's 8:00 p.m. here in Greece but this afternoon. I mean, I really want to thank you, Professor Cottrell, for inviting me here. I'm very honored to be here, to be invited, very excited, to be presenting here in the Ability Grand Rounds at the West Virginia University.

So, yeah, just a brief description of myself and the setting. I am a white man in my 40s. I have a black beard and black hair, and behind me is a white wall, to my

left-hand side you can see a bookcase.

And today, I will be talking about cancer and disability, basically, about disparities that people with disabilities face when accessing cancer care, not only in the U.K., not only in the U.S. but more generally but I will be using examples from my own research in the U.K. mostly and also data from the U.S., mostly taken from the CDC database.

So I will now share my screen. And I hope it's going to work. I'm sure it will. Let's see.

>> LESLEY COTTRELL: We see it. Thank you.

>> DIKAIOS SAKELLARIOU: Perfect.

So the title of the talk is: Cancer Disparity for People With Disabilities: Bridging the Gap. So this points I guess to the dual aim of my talk, so the first one is to provide an overview of cancer disparities faced by people with disabilities, and then I also want to talk about what can we do about it?

We know things are not great. We know people with disabilities face many barriers, accessing health care, and specifically cancer care, so I'll be talking a little bit about what we can do, things we can do to bridge that gap.

So just to give you an overview of the objectives of this session, and the things we will be covering, first is an overview of cancer disparities faced by people with disabilities. It's related to service access so I'm not going to be talking a lot about disparities for example in terms of outcomes, disparities in terms of mortality. I might be touching upon those, but mostly it is about disparities regarding service access.

We will explore the reasons underpinning those disparities. What's going on? Where do they come from? Why do we have those disparities?

[Background noise]

And then the last part of the talk will be about identifying strategies that could lead to more equitable cancer care.

And the presentation overview more or less follows those objectives, so I'll be talking about, you know, the problem, what is the problem? Which is the disparities that we know people with disabilities face when they seek to access health care, and more specifically, cancer care.

I will be talking about the barriers underpinning those disparities, and then what can we do to make things better?

So we know that people with disabilities is not a minority population. For many years it was a commonly held misconception that when we're talking about disability inclusive health care, architecture and design, that this only referred to a small fraction of the population. That's simply not true. People with disabilities form about roughly 15% of the population, but that really depends on the kind of definition we use for disability, and the different classifications.

So you see on the bottom left side of the slide, that 26% of adults in the U.S. have some type of a disability. In the U.K., it is about more or less the same, 20 to 25%. And that's in part may have to do with, you know, more refined diagnostic procedures, more rigorous classification, which means that more people get diagnosed, but also obviously with longer survival rates, longer life expectancy, and as people we know that there is a very strong relation between age and disability, so as people live longer, then they're more likely to develop some sort of an impairment that will lead to disability.

But despite the fact that a substantial proportion of the population have a disability,

experience a disability, and this is only growing, disability's often overlooked, both in health policy and in research on health access, so we often see research where we don't see any sort of disaggregation, for example, by disability, and in fact, we often see research in health care and health care access where people with disabilities are actively excluded, because it would be a confounding factor according to commonly held misconceptions or conceptions in research, which means, though, that often their needs, their experiences, the voices of people with disabilities remain invisible, and you see on the right-hand side of the slide that report co-produced by the London School of Hygiene & Tropical Medicine in the U.K. and the World Health Organization the missing billion. Roughly 1 billion people with disabilities on earth, and we don't know much about their needs. We don't know much about the specificity of access to health care for this population. In relation cancer now we know for example that while people without a disability in the U.K. may have, sorry, have a very small screen here in front of me so I need to lean forward to be able to read what's on the screen. So while we know that adults with no disability have a prevalence for cancer of 5.2%, people with a disability have an age adjusted prevalence of 8.7% so it's substantially higher, and yet in most of the research we see about access to cancer services, cancer outcomes, or cancer related research we hardly see any disaggregation by disability or any specific attention to the needs of this population. Of course, there are exceptions and there are researchers doing that but it's not mainstream yet. [Inaudible] has spoken about social disparities in cancer so defined as health inequities that involve social inequalities in the prevention, incidence, prevalence, detection and treatment, survival, mortality, and burden of cancer so in all aspects of cancer really and we see that these social disparities in cancer, they're also there, they also exist for people with disabilities, and later on as the topic goes on we're going to examine specific instances mostly in relation to the detection and treatment, so access to services basically of cancer, but we know there are inequalities in the other areas, as well.

So what is the problem? So we know that people with disabilities experience disparities in access to health care services in general, not specifically or not only cancer services.

And access to health care is a very complex issue, because health systems are very complex construct, and the more complex they get, the more complex access to them is and it has many components.

So for services to be accessible, they need to be first of all available. Then they need be there. We need to have services in order for them to be accessible. There need to be services that respond, that are there.

They need to be affordable. And that can mean many different things depending on the nature, the structure and the financing of the system, but basically people need to be able to pay for those services, without incurring catastrophic health expenditure. They need to be relevant. They need to respond to people's recognized needs. They need to be physically accessible, and that refers both to the need that people need to be able to go from wherever they reside to a health care facility, but also within the health care facility they need to be -- there needs to be physical accessibility. So for example I've heard stories in my research about, you know, really well-designed hospitals, health care facilities, transportation and all that, but then no accessible toilets, so that doesn't -- that means that a health care facility is not accessible because it's not

only about having wide enough doors, for example, or visual cues or auditory cues for people. They need to cater, they need to respect and acknowledge the needs of people with disabilities.

And finally, health care services need to be acceptable by people with disabilities and by every user really, and that means that people need to be treated with dignity. People need to be treated with respect. People need to be listened to.

Now, we know that in the U.S., that 1 in 3 adults with disabilities and by adults in this case we mean people between the ages of 18 and 44 years of age, so 1 in 3 adults with a disability do not have a usual health care provider. 1 in 3 have an unmet health care need because of cost in the past year. And 1 in 4 did not have a routine checkup in the past year. So you see here in this diagram, which is from Levesque, a researcher from Canada, they outline the different stages if you want and the different components of access to health care and we see on the bottom here of the arrow health care needs and people both need to be able to perceive the health care needs they have but also there needs to be an approachable service which will allow people to do something about those needs. Then people need to have a perception of those needs and the desire for care. They need to be able to seek health care, to reach health care, to use it, and we're talking both primary and secondary access, and then we the health care consequences, what's happening at the end of this process, and all along you see on the top-hand side, you see the -- [Background talking]

The system based if you want values or the system based components so approachability, acceptability, availability, affordability, appropriateness and then at the bottom -- [Background talk]

The other side of the arrow we see the individual level factor. There is increasing evidence that people with disabilities face problems in several of these decisions leading to inequalities in access, where health outcomes, reduce the utilization of general services compared to the general population and we know that this intersection -- [Background talking.

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We know across the world people with disabilities face increased levels of poverty, and lower literacy and education levels, and also such structural disadvantage intersects with ableism so discrimination against people with disabilities, and the generalized expectation that discrimination against expectation that all can or ought to conform to the idealized non-disabled norm. The buildings, attitudes are not really geared towards the needs of people with disabilities. If we see here, really what I want to show is the problems that different parts of the population in the U.S. have accessing a medical doctor due to cost and this data is from the disability and health database from the CDC. And it's from 2018. So a man without a disability had, or if you want, there was an 8.4% age adjusted prevalence that a man without a disability would not be able to see a doctor because of -- due to cost in the U.S.

That goes up to 11% for a woman without a disability.

And it more than doubles for a man with a disability, up to 24%. And even higher for a woman with a disability, so you see that first, disability is a very important factor here, so we go from 11% for able man without a disability to 24% more than double for a man with a disability but also gender and we see gender as a factor in both categories, both for people without a disability from 8.4 to 11, and for people with a

disability, from 24% to 26.8 here, and of course there is geographical variation as well, which not being entirely familiar with how the health care system in the U.S. works and the federal how each state organizes its health care, I cannot comment on that, but there is definitely a variation there across states, and what is becoming quite clear is that states here in the southern plain or people in this area, report -- have a higher prevalence of unmet need due to cost.

And COVID doesn't make things any better, really. This is a webinar organized by the American Bar Association towards the beginning of the pandemic, and there they discuss, we're not talking about it now but I thought I'd post the link here so people can watch it later in their own time. I think it's about one hour long, and it's very interesting. It makes for some very interesting, if not very happy, viewing.

And they discuss the issue of rationing of life saving COVID treatment and who gets left behind the discrimination faced by people with disabilities in the face of COVID, and we have encountered this across the world, in the U.K., where people with disabilities were forced to give do not resuscitate orders, and or permissions, and in other places where people with disabilities were either denied life-saving treatment or they didn't have -- they were not high up in the priority, or they were not seen as -- they were basically, yes, they were not seen as a high-priority patient.

So this is the, if you've want, the overall context.

But what is interesting to note is that this is -- these inequalities in access to health care are encountered across the world in many different -- in countries with quite different health care systems, so for example, in the U.K. where we did a study a few years ago, there was very similar issues with men and women with disabilities reporting increased barriers to access in health care, and with women with disabilities reporting higher level of barriers compared to men with disabilities.

And the U.K. has a completely public health care system, entirely free, at the point of access. And several similar issues were encountered in Greece, as well. Greece has more of a hybrid system. Most people would have access to a public health care system, which is free at the point of access, but they would also use private health care on the side to expedite access, to have better access or better service, or for a variety of other reasons.

And also in Chile, which has yet a third kind of system, it has a dual system where people need to choose between public or private health care, but they cannot mix and match. They cannot combine. They need to choose one or the other.

But across all those three countries, we encountered similar patterns of inequalities, similar patterns telling us that there is something going on, people with disabilities face increased barriers. People with disabilities face increased problems when they seek to access health care, and they report higher unmet needs compared to the general population.

Now, in relation to cancer more specifically, to disability cancer disparities, we know that people with disabilities are less likely to utilize cancer screening services, and they're more likely to report barriers in access to cancer services, compared to people without disabilities.

Excuse me.

They also report lower satisfaction and lower use of services, again compared to people without disabilities. So again, we see data from the Disability and Health Data

System from the CDC, and if we look at the use of mammograms in the past two years for women, you see here the difference between women without a disability have 81.1% prevalence of having used the mammograms in the past 2 years and women with a disability that had a 74.4% prevalence of having used a mammogram in the past 2 years.

And this data is a bit dated now, is a bit older from 2009 from the National Council on Disability, and a report they produced on the Current State of Health Care for People with Disabilities, but then you see here that utilizing pap test was inversely related with severity of impairment, so that women with more complex what they termed more complex limitations had lower access, lower utilization of pap test compared to women with no disabilities, or with less severe or less complex limitations.

And similar patterns of disparities are observed globally across different health care systems. So there is evidence that people with disabilities experience worse access to cancer screening, not only in the U.S., but across the world, and even in countries with universal health coverage and public, free at the point of delivery health care, like the U.K. And there are various studies underlining the existence of disparities in cancer treatment and also substandard experiences of service provision which then creates, if you want, a bad precedence, and then people who have had a bad experience with, for example, cancer screening do not want to return for a repeat appointment, because they have a very bad experience.

This is a large prospective study from England and again it shows basically it's more evidence about those disparities in access to screening. It shows that women with disabilities in the U.K. were less likely than other women to participate in breast cancer screening, and also in bowel cancer screening. And a study I was involved in also in the U.K. showed very similar results that women with a disability, or specifically mobility impairment, had lower odds of having a mammogram than women without mobility impairment.

And similar patterns, we see similar patterns of risk use with respect to screening. Cancer is one important aspect, because it's heavily linked to prevention which is very important in cancer, but also we see disparities in terms of access to treatment. So we know that women with Social Security disability benefits and Medicare coverage have lower rates in this study of breast conserving surgery than other women and among women who had breast conserving surgery women with SSDI and Medicare coverage were less likely than other women to receive radio therapy and axillary lymph node dissection and women with SSDI and Medicare coverage had lower survival rates than those of other women in all-cause mortality and also breast cancer specific mortality.

And also similar results here, with lung cancer from this study, and persons with disabilities are significantly higher cancer specific mortality rate than persons without disabilities and those persisted after adjusting for demographic -- for demographic and tumor characteristics. So there is something else going on there, as well. So we know people with disabilities face many barriers that affect both access to screening and access to treatment.

But what are these barriers? Well, there are many. They are complex. They correspond to those different areas that I mentioned earlier on, the different areas of access, and they have to do, for example, with inaccessible health care facilities and/or equipment, so health care facilities that do not accommodate the needs of people with

disabilities, and also equipment that does not accommodate the needs of people with disabilities, and we're going to see some specific examples in a few moments.

Lack of social support, and often that is very important. Support that help people get from where they live to a health care facility, for example. Financial constraints, and these have to do with, well, paying for health care services in systems where payment is required for such services, at the point of use, but also paying for medication, paying for equipment, paying for care, paying for everything else that basically having cancer is not cheap, and having a disability is not cheap either, and those two coming together create, as we know from existing research, create structural or if you want, financial disadvantage for people, and they create costs that are not always recognized.

Past negative experiences with health care professionals is an important one, as well, and there is research indicating that it's basically women having a mammogram or a Pap smear test that due to past negative experiences, due to experiences where they felt not -- they were not listened to, or the procedure was painful, uncomfortable, the equipment was not really, you know, could not adjust to their needs, they report past negative experiences that stops them from returning, stops them from going back. They think that this is not from them, because the system doesn't really -- doesn't appear to be accommodating their needs, and this is tied to discomfort, as well.

And also, inadequate information. There is research indicating that women with disabilities is basically do not receive the information they need about, for example, the need to perform mammograms or Pap smear tests. Lack of appropriate, lack of or inappropriate transport is very important, as well. I mean, people need to get to health care facility and importantly, they need to get back home, as well, after their appointment.

In a study we did in the U.K. a couple of years ago, there were people saying that, you know, there is hospital transportation to get them to the hospital, that is fine, but then they need to wait around for hours after their appointment, because the transit, the transport, has specific times that will carry people, so sometimes people might finish their appointment by 10:00, 11:00 a.m., and then they need to stick around till 5:00 or 6:00 p.m., which is not a very pleasant thing to have to do, and also sometimes it's an impossible thing to have to do, especially if people need to go home and rest or conduct other procedures.

And finally, but very importantly, what comes through is inadequate training of health care professionals. Health care professionals not knowing how to respond, how to address to the needs of people with disabilities, to the needs of people with disabilities diagnosed with cancer.

A group of researchers from Sydney, from Australia, Gwyneth Llewellyn and her colleagues, they talk about intangible barriers to participation in mammography screening so they talk about those barriers that have to do with the attitudes of health care professionals, have to do with how the sort of interaction that goes on behind closed doors sometimes so they start by saying that when people enter a health care encounter, when people access a service in this particular instance, breast cancer screening, services, mammography, they have the expectation to be appropriately informed. They have the expectation to be appropriately involved in the care they receive and they have the expectation to be treated with respect. And they say that

they found out from their study that there are problems, difficulties, inconsistencies across all those three expectations, which meant that women were not -- were made to feel that this was not for them. They were made to feel that health services, or breast cancer screening services, were not disability-inclusive.

And behind statistical figures, behind all the numbers we have about cancer screening, there are actual human stories of people who tried to access health care, tried to seek health care because they were worried about new, unfamiliar symptoms, but then whom the doctors then were reluctant to diagnostic overshadowing, wheelchair users being asked to stand up, and health care professionals not exploring ways to adapt processes to make them disability-inclusive, and that this exemplifies a general lack of disability inclusiveness in the provision of health care services and more specifically the provision of cancer services.

And just very quickly, I'm going to show you some examples from different sources of information. This is from this report from the National Council on Disability, the Current State of Health Care for People with Disabilities, and you see here this quote from a focus group that says --

In one particularly troubling instance, a provider's value judgment about a patient with mental retardation led to a year-long delay in treatment for a life threatening medical condition. The patient suffered from advanced breast cancer that required surgery, but her physician implied that due to her already low quality of life, owing to her disability, she did not merit the intervention, and her guardian did not want to make the decision to go forward without the physician's support. This woman reportedly died within a year, and there was concern that her death may have been precipitated by the delay in surgery. So there are many things that are wrong here but what I want really to highlight is this, the, where is it, the already low quality of life.

So that -- I mean, makes a huge assumption that a person makes on somebody else's life, and also the very significant repercussions this had in this case.

This one is a quote from a study we did in the U.K. about access to cancer services for people with disabilities. And you see this quote from a guy, Jonathan, who was 50 years old, and I'm going to read out the quote, and it says --

A doctor wanted to check my bladder was okay, so I went off to have a series of tests. And one of them was a test where they filled my bladder with radioactive dye so it would show up on an x-ray and then they were then going to watch me empty my bladder to make sure that it emptied properly. And so I went in. There was no changing room for a wheelchair user so I had to change in the toilet. And then there was no way of getting me on to the table, so if I hadn't been able to transfer there was no hoist or anything. I then had dye thrust down my penis into my bladder and then I was told, right now stand up and go to the toilet.

And it was sort of like, did you not notice that I've just wheeled in in a wheelchair? And it was like, well, we can't do it any other way. And I still haven't had that test. I'm still no nearer. So this is a particularly again shocking example.

There was a man using a wheelchair, and that wheelchair became invisible somehow. He was asked to perform things that he could not, and then he couldn't get the test that he need, because of that, and there was no problem-solving around that. There was no exploration of other ways to do things, or other possibilities there.

And then we see this final one, which I'm not going to read out but it's for you to

read out if you want, because I'm aware of the time, as well. But again, all these stories point to ableism, discrimination of people and ableism, to discrimination that people with disabilities face to the expectation that their bodies should perform, should operate, should function exactly like everybody else's and this idea that there is a normative body, a body that must be able for example to stand up and empty one's bladder standing up, the idea that people must be able to climb on to examination tables, so this idea that there is a certain kind of body that the services respond to.

And we see here that even when people do access services, diagnostic overshadowing, that is, the mistaken attribution of new symptoms to a patient's preexisting disability, may delay or completely preclude diagnosis, so there are many examples of this but I've chosen this one again from the National Council on Disabilities report from 2009.

About a 42-year-old woman with paraplegia noticing a lump in her right breast and her medical provider telling her it is a bulging pectoral muscle from pushing the wheelchair so she was later diagnosed with stage 3 breast cancer and she died within three years of this delayed diagnosis.

So there are many barriers that people face and last year we did a systematic review looking specifically into the barriers that people with physical disability face, and I'm aware that this doesn't capture the complexity of all people with disabilities, but it shows the variety, you've want, and the breadth of the different barriers that people face, and I'm only going to highlight a few, the ones that have the -- on the column on the far right shows the confidence level, so the M is medium, and H is high, and then L or VL is low, or very low.

So I'm only going to highlight a couple of them. So for example, let's see. Interactions between health care providers and women with disabilities, attitudes and behaviors, that had a high impact and high negative impact on people's access to health care, so men and women with disabilities reporting that health care professionals lacked knowledge about disabilities, that also had a high confidence rating so that was an important issue. What else? Economic concerns had quite high importance.

Gatekeeping, which is very troubling and worrisome, so not all providers suggested or recommended referrals for primary health care procedures for women with disabilities, including cancer screening, and many others that you can see. The report has been published so you can look it up and you can see the barriers in detail.

So people with disabilities often need to navigate a health care system that demonstrates a basic lack of awareness, a fundamental lack of awareness, of disability, and it appears to be inadequately equipped to meet the needs arising at the intersections of disability and cancer.

And I've touched upon some of those issues before earlier, but the main problems have to do with normativity expectations where people are expected to operate, people's bodies, are expected to operate, to function in specific and similar ways, and a widespread lack of disability awareness and/or training. Discontinuity of care, which is particularly at least in the study we did in the U.K. was particularly important, because people's care, medical care or health care, was fragmented across many different providers who didn't communicate a lot between them. It meant that there was a fundamental discontinuity of care, and sometimes there were interactions for example between a treatment taken for cancer, a treatment taken for an underlying impairment.

Individualization of disability, and alongside that, the responsabilization of people with disabilities whereby disability and access to care becomes an individual responsibility. People need to sort it out themselves. It's their body, it's their problem so that individualization means that the broader structural issues that impede access to health care get disregarded.

And you see that we can see that across many of those levels of access to health care, you know, the individual, or the individual responsibility, is only one part, really. The systemic issues here, the systemic factors, are very important, as well.

So what can we do to make things better? How can we bridge those -- how can we begin to bridge the gap? So we need a multifaceted, we need a multipronged approach. First we need to provide disability inclusive health care, including cancer services, of course. Secondly, we need to explore and to reduce, we need to explore the screening underuse and increased cancer incidence. Basically, we need data. We need visibility. We need to know what's happening.

And finally, education and training of health care professionals, so they're disability-aware, disability-knowledgeable, and I don't know if I'm running over time, but I have a couple of minutes more just to -- I see Lesley nodding so I take that as an okay.

[Laughter]

It is important, it is necessary, to make all health services disability-inclusive and the worrying thing is that despite extensive legal protections both in the U.S. with the Americans with Disabilities Act, and in many other countries, in the U.K. with the Equality Act, across the world with the United Nations Convention on the Rights of Persons With Disabilities, to which the U.S. is a signatory, the U.K. is a signatory, so despite those legal protections, people with disabilities still often experience multi-faceted de facto discrimination leading to compromised health care. This needs to change. We know what needs to be done, for example, for services to be accessible, and this needs to happen right from the architectural point of view, but also more broadly in terms of making them affordable, making them available, making them relevant, making them appropriate, making them acceptable.

Barriers encountered at each of these levels must be identified and addressed.

Sorry. Yes, so secondly, it's visibility. We need to know what's happening basically. We need to have figures. We need to have disaggregated data for people with disabilities, and at the moment, there is an invisibility or often there is an invisibility of this population in cancer statistics.

So for example, the recent extensive information for example regarding stage of diagnosis for people with disabilities. We don't know if there is or isn't a substantial difference or significant difference for example regarding stage of cancer at the point of diagnosis between people with and people without a disability.

I mean, the screening underuse suggests there might be, and it suggests that people with disabilities might be diagnosed at a more advanced stage of cancer because of the reduced use of screening but we don't know for sure.

At the very basic, all cancer data should include the Washington Group questions, and the Washington Group questions is a group on Disability Statistics, and they have the short set of only, I can't remember, 5, 6 questions that can provide at the very least some much-needed visibility of this population, and then we can look into the interaction between factors of age, disability, within geographic influences, government policies at

the broader ecological level, if you want.

And finally, education. It's very important, and I know it is lacking because I myself, I teach in a school of health care sciences in Cardiff in the U.K., and I know that we don't have any disability-specific courses. I know that there is nothing to specifically prepare people, specifically prepare the medics of tomorrow, the physiotherapists of tomorrow, the Occupational Therapists of tomorrow, to be disability inclusive in their practice, to address the needs of people with disabilities in their practice. It is so very important to include people with disabilities in that, to listen and learn from their experiences, to know what is happening, to know basically what will help and what will not and what will not help. And better communication between the various professionals and across the different teams involved in a patient's care is of course, very, very important and can also help raise awareness on how disability can interact with cancer-related care.

And of course, we need more accessible environments including screening equipment, such as that used for mammograms and treatment processes such as radio therapy.

As the population ages and we have an increasing number of people living with cancer, both with cancer and with disability, it is more imperative than ever that cancer services are disability-inclusive, and again, I repeat and I insist that this must happen for all health care services.

Early and fast diagnosis, equity of access to treatment and care, and inclusive health promotion campaigns are key for the development of health care services that better respond to the needs of people with disabilities.

And we know that improving cancer outcomes is a very complex enterprise, a very complex endeavor, and it cannot be realized without the explicit consideration of people with disabilities and their participation in the decision-making processes.

For one thing, it's illegal to not include, to not be explicitly disability-inclusive in health care services. And also that it's impossible to achieve better cancer outcomes seeing that people with disabilities form a proportion of between 15 and 25% of the population in most, at least in most high-income countries, it's impossible to achieve better cancer outcomes without explicitly addressing the needs of this population.

So here is my email and my Twitter handle for those of you who want to get in touch. And they very much.

I will stop sharing the screen now.

>> LESLEY COTTRELL: No, thank you for a great presentation. I'll open it up for any questions or comments that people have, and then I know that people are saying thank you for a great presentation in the chat, as well.

>> DIKAIOS SAKELLARIOU: You're welcome. And I'm sorry if I went slightly over time.

>> LESLEY COTTRELL: Oh, please. No, no, we didn't get you started on time so you're welcome to that extra. Thank you. Does anyone have any questions about -- yes, Grace, I see your hand.

>> Hi. I had a question. I know that one other potential barrier for health care services that can exist among lots of different populations is gender identity and gender-affirming care. I wonder if there are data about trans or non-binary components of access to disability care? And I know that this can be especially tricky

worldwide where some of that isn't recognized legally.

But just considering the male, the female, wondering if there are any gaps in there that we should also consider.

>> DIKAIOS SAKELLARIOU: I think that's a great question. I'll start by saying: I'm not aware of any data. I know I did look very recently actually, I was looking into some data, about access to general health care for non-binary people or trans people and as I'm sure you know, the statistics, that data doesn't look very good. People experience discrimination for many different reasons.

I haven't seen anything specifically about people with disabilities who identify as non-binary or trans, but I would be very interested to look at that. I mean, I imagine that there will be added discrimination, an added vector of discrimination there, but I don't know. I have no -- I do not have any data, I'm afraid.

>> That's all right. Thank you.

>> LESLEY COTTRELL: Thanks, Grace.

Any other questions? I do find -- go ahead, Elizabeth.

>> This is a little bit granular, so I'm wondering, of course, it's absolutely valuable to have education campaigns for service workers, health care professionals across the board absolutely, but I'm wondering to what extent it was looked at either in any of the studies you mentioned or if you know of anybody else looking at what role that public education plays in that.

So education for the public. Specifically about cancer and maybe about other diseases or illnesses and related to disability. Are there any campaigns? And can we break that down to geographical region?

So maybe some of the effects that we're seeing happen in combination with all of the disparities and what's happening within the health care system but to what extent does public education about Public Health play in that either nationally, internationally or within regions?

>> DIKAIOS SAKELLARIOU: I think that's a very important -- thanks for bringing that up. I think that's a very important point, definitely. I haven't looked into that in my studies. I -- and I don't know really, but I imagine that it would have a very important effect, also because public would know -- often Public Health initiatives are not disability inclusive so they portray certain kind of citizen and certain kind of service user that is not necessarily always the -- what I remember from, we did a study in Chile in South America a few years ago and I remember that a comment that often people were saying was that, mammograms or Pap smear tests were not for women with disabilities.

And I imagine there is lots to do with that Public Health campaigns there and Public Policy campaigns, and also that connection that for one hand between sexual activity and cervical cancer and also between disability and asexuality, not engaging in sexual activity. I mean, both of them mistaken assumptions obviously, both of them misconceptions, that can have tremendously negative impact on people's lives.

>> And they could be so intertwined too because people within regions within health care, they aren't in a vacuum. They live in those communities and they'll have the same prejudices and biases and misunderstandings that the general population has. So it's not that it's just health care professionals that don't know, or don't know better.

>> DIKAIOS SAKELLARIOU: No, it isn't, you're right, it isn't. Because if you -- because access to health care service has a lot to do with the communities that

we're all part of, and if we see everybody around us doing something, we're more likely to do it, as well. Or if we are recognized as eligible for that service, we're more likely to do it as well.

But I have no data about that, the interaction between the two. I don't know if it exists. I hope it does but I'm not sure.

>> Thank you.

>> DIKAIOS SAKELLARIOU: You're welcome. Thank you.

>> LESLEY COTTRELL: I do want to add something. I think our role, we're talking a lot about medical providers, but your presentation and the data point to it's not just enough for us to refer someone to a service. So if they think they might have cancer, it's not just enough to refer them to a provider in the area. It's actually something that we could do, is to make sure that that message gets to that provider that -- and with HIPAA and all of the other stipulations, but that to try to educate them and make sure that that linkage is appropriate.

I do know it's interesting with cancer, for me, because when a person starts, or at least from our cancer partners, when the person starts that journey and then identifies that they have a cancer diagnosis and then starts treatment, so that's assuming that they didn't have a disability going in, and then they develop a disability as a result of the treatment or the cancer itself, you wonder if they would still have issues. How do they deal with follow-up paps? How do they deal with follow-up mammograms or anything like that, now that they might have a disability? Whether they're in a wheelchair, or whatever the case. So I wonder longitudinally someone who didn't have a disability, has one as a result of the cancer, what would their experiences be with the same providers they started with? Right?

>> DIKAIOS SAKELLARIOU: Yeah. Exactly, because the way they access them, because the way they access, the way they enter the system will have changed.

>> LESLEY COTTRELL: Mm-hmm.

>> DIKAIOS SAKELLARIOU: The way they're looked at from the system or from providers will have changed, as well.

>> LESLEY COTTRELL: Right. And the providers I'm sure know that the treatment or the cancer effects, right, they readily -- but what you're talking about is more of the impact on daily living. It's a different level like you and Elizabeth were talking about, a different level of understanding.

>> DIKAIOS SAKELLARIOU: I'm sure it happens quite a lot. Because cancer and cancer treatment as well, they can lead to disability. They can lead to impairment and it's a common occurrence so I'm pretty sure it's more common than the published data or the published literature leads us to believe.

>> LESLEY COTTRELL: This is really interesting. Thank you. Any other questions before we let you have your evening back? It's late there.

Any others?

You have a lot of great comments in the chat. Thank you for the presentation, the examples you provided are heartbreaking but lessons learned there. Opportunities for us to improve our training, and as a center of disabilities and partners related to that, there is definitely a lot that we can do there.

Okay, well, thank you so much for joining us.

>> DIKAIOS SAKELLARIOU: Thank you. Thank you for inviting me. I mean, it

was a great evening for me. I hope you enjoyed it, too.

>> LESLEY COTTRELL: Good. We did. Have a good night.

>> DIKAIOS SAKELLARIOU: Bye-bye. Thank you very much. Goodbye.

>> LESLEY COTTRELL: Thanks, everyone.

[End of session]

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