

Speaker 1: The HD Insights Podcast is brought to you by the Huntington Study Group. The Huntington Study Group is a nonprofit research organization dedicated to conducting clinical research in HD, and providing critical training on HD to healthcare professionals. Funding [00:00:30] for this podcast is made possible through the generous support of listeners like you and sponsorship grants from organizations like Genentech, Teva Pharmaceuticals, Neurocrine Biosciences, UniCare, Vaccinex, and WAVE Life Sciences.

Host (Kevin Gre...: Hello and welcome to the HD Insights Podcast. I'm Kevin Gregory, Senior Director of Education and Communications for the Huntington Study Group, and today I'll be joined by Dr. Nicolò Zarotti. [00:01:00] Dr. Zarotti worked on the first national guidance and psychological interventions in the United Kingdom for people with HD, ALS, Parkinson's and multiple sclerosis which was recently published by the British Psychological Society or BPS in liaison with Lancaster University. Originally from Italy, Dr. Zarotti moved to the UK to pursue a PHD at Lancaster University investigating emotional processing and communication in people with [00:01:30] Huntington's disease. This was followed by a post doc on ALS at the University of Sheffield.

He's currently pursuing a doctorate in clinical psychology at the University of East Anglia while continuing to carry out research on psychological approaches to neurodegenerative diseases like Huntington. On this episode Dr. Zarotti speaks at length about the guidance and psychological interventions, what he learned throughout the course of that research and why he considers that publication a call to arms for the criticality [00:02:00] of psychological support in HD care.

All right, Dr. Zarotti, thank you so much for joining us here on the HD Insights Podcast. I really appreciate your time today.

Dr. Zarotti: Thank you for having me. [inaudible 00:02:17].

Host (Kevin Gre...: Absolutely. Now, before we get too far into the specific aims and the focus of this recent work, can you first tell us about the genesis of the research? What was the inflection [00:02:30] point that really brought into being?

Dr. Zarotti: Okay, absolutely. So, we, as a group from Lancaster University, we got really interested in developing resources for people with motor neurone degenerative conditions in general and we eventually focus on four motor neurone degenerative conditions, in turn psychological interventions, which includes obviously Huntington's disease but also Parkinson's, multiple sclerosis and motor [00:03:00] neurone disease. Now, motor neurone disease is also the term we use in the UK for what is more commonly referred to as amyotrophic lateral sclerosis, ALS in the US. What we wanted to create was a guidance for... the first UK national guidance in fact, for these kind of conditions because there is quite a paucity of [inaudible 00:03:29] at the moment. [00:03:30] There is some variance between the conditions. We can talk about that a bit later but as an

overall attitude towards these conditions I have to say, I didn't really see much evidence.

We didn't really find much evidence for psychological approaches and that can be for a number of reasons, I believe, but HD in particular is the condition where we found [00:04:00] the smallest number of [inaudible 00:04:03]... piece of evidence. So I'm particularly keen on the drive for HD really, because that's the condition I did my PhD on, and I really believe that should receive way more attention than it does now from a psychological perspective. I understand that there is a lot of drive, as it's very understandable, [00:04:30] for finding a cure but we need to understand also that HD is a long term condition. It's a chronic condition. People get diagnosed half way through their lives, if we don't count juvenile HD, and they live with the condition sometimes for the better part of their lives. So there is obviously a strong need for a cure but also a strong need for finding ways to improve quality of life because people still [00:05:00] need to live with the condition for many years to come.

So yeah, that was the reason why we approached these conditions, because most of them, apart from motor neurone disease and [inaudible 00:05:13], which is a bit different in terms of prognosis, these conditions are not really covered by the psychological [inaudible 00:05:23] clinical psychology [inaudible 00:05:25] in terms of interventions as much as they should because these [00:05:30] people suffer from conditions that will impact their lives for many years and they need psychological support for many years.

Host (Kevin Gre...: By including all four of these conditions in this research, did that make it more complicated by adding scope or did it actually make it easier for you to consolidate and focus on the things that you were trying to learn through the research?

Dr. Zarotti: Well, I would [00:06:00] say that generally speaking it made it easier in a way because some of the features are very similar, so when we focus on motor neurone degenerative conditions we focus on conditions that, first of all, affect the motor system, affect the way people move. And in a way there're a lot of similarities between Huntington's, Parkinson's, [00:06:30] ALS and then there's... I would say, probably multiple sclerosis is a bit of a... the odd duck in that context. The one [inaudible 00:06:41] because of the age of onset, it tends to be younger but then again, the impact the condition can have can be very similar to some of the juvenile variations of Parkinson's and Huntington's for example. If you think of juvenile [00:07:00] HD, it tends to have an onset around the same age as multiple sclerosis, so in that sense, it helped in trying to get a wider understanding of how the literature has approached in these conditions.

And at the same time, I believe, also gave us the possibility to look into other conditions when evidence was lacking for specific ones. So for example, in the specific case [00:07:30] of HD, having seen the evidence for Parkinson's and motor neurone disease, multiple sclerosis, has been quite helpful in terms of

trying to push things forward because... at least we could rely on some evidence that was based on conditions that share some similarities with Huntington's. So we were not just saying, "We need more research," but we were giving new ideas of what to do research on. We can actually say, " [00:08:00] We need to do a research on Huntington's," and that could be inspired by the research that's been done on Parkinson's disease, the research that's been done on amyotrophic lateral sclerosis. So I would say that it's most an advantage rather than disadvantage to group them together. Obviously all the guidance bits, the suggestions need to be tailored for each individual condition because even though they share similarities [00:08:30] they're definitely not the same.

Host (Kevin Gre...: That makes sense. So let me ask you this, what do you think or why do you think the psychological aspect of Huntington's disease has really been lacking, kind of the standardized guidance for approaching those issues?

Dr. Zarotti: That's a very good question and I don't think it's an easy one to answer. I think, in a way, that there is a general... as I said, there is a general [00:09:00] tendency to underrate the importance of psychological interventions for these kind of disease in general, not just Huntington's. I think Huntington's... I think HD suffers, generally, from a lack of awareness and that can be for multiple reasons but I think one of the strongest reasons is that unfortunately HD never had quite famous patients [00:09:30] that promoted the awareness for the condition. If we see... again, compare it to other motor neurone degenerative conditions, you take Parkinson's disease, you take amyotrophic lateral sclerosis. Parkinson's disease is way more common than HD so Parkinson's tend to know it but then you have very famous like Michael. J. Fox who actually got juvenile Parkinson's disease and created the Michael. J. Fox Foundation [00:10:00] and expanded awareness for the condition massively. You had Pope John Paul the second, you had Muhammad Ali, a plethora of very famous people who made the disease known to the public.

Amyotrophic lateral sclerosis is less frequent but then again we had quite a few famous patients that promoted its awareness. We had Steven Hawking, in the US Louis Gehrig. Actually [00:10:30] I think it's still sometimes called as the... called Louis Gehrig's disease in the US. So it was actually named first after a very famous sportsman. And it tends to affect sportsman more selectively, so that is eerily a bit of an advantage because then people get to know it. Huntington's, I did my PhD as I said on Huntington's and for the entire duration of my PhD I really struggled to explain it to people who asked me [00:11:00] what I was doing. What Huntington's was off the top of my head because they'd never heard of it. They'd only heard of Huntington's if they ever studied genetics or something related to genetic conditions but there is a lack of pop culture references, for example. Huntington's features in a couple of episodes of Scrubs or House MD and that's what I used for pop culture references but in general [00:11:30] psychological intervention seem to arrive after medical focus, medical interventions.

And again, I would say in a way it's understandable because first of all you want to find a cure but I would say it's also driven by awareness. It's driven by the awareness that there are people out there that need to live with this condition for many years and the fact that people don't know that Huntington's is... Many people don't know [00:12:00] that Huntington's is a condition that many people have to live with, probably has an impact on [inaudible 00:12:07], partially explains the lack of psychological literature so far. On the other hand, I also believe that there's... [inaudible 00:12:17] a self-critic here, as a psychologist I think that for many years, psychological interventions have thought of some severe neurological conditions as [00:12:30] non-treatable and there has been [inaudible 00:12:33] on psychiatry as opposed to... especially neuropsychiatry as a framework as opposed to psychological theory.

Now this is a bit changing at the moment, thankfully, and we hope that actually our research helps promote this change, but if we look at the inference, the leading framework around psychological difficulties [00:13:00] in people with HD in the past 20 to 30 years, that's been mostly neuropsychiatric. And by neuropsychiatric I mean, mostly a medical model, as in explaining all kinds of psychological difficulties as medically derived, so as organic changes in the brain. Which, by no means I mean that they're not due to that at all but [00:13:30] they also don't explain all psychological difficulties because we now know there is a lot of psychological aspects in terms of adjusting to the diagnosis, adjusting to the stress caused by the diagnosis, the disease or the relationship with other family members considering especially that HD is also more dominant. So people who get tested, people who get the gene mutation, people who don't, [00:14:00] having that sort of conversations in the family, there is a lot going on that goes well beyond the medical model, and go beyond just some neurological changes. And this has been receiving attention just very recently.

Host (Kevin Gre...: Yeah. That makes perfect sense and it's interesting that you draw in the experience of those other diseases really having [00:14:30] that prominent social figure that kind of drove awareness. And I know Huntington's disease often looks to Woody Guthrie and that's somebody that is very well known but also somebody that was... many years ago and you don't have that contemporary right now driving interest like you do with Parkinson's or with ALS, things like the Ice Bucket Challenge that kind of [00:15:00] help drive awareness. How much of it do you also believe too? There's historically been a stigma around Huntington's disease and it being a family disease. Do you find that it's prevalent in these other conditions or is it something that really bears it's brunt with HD?

Dr. Zarotti: That's hard to answer. Well, first of all I'm not an expert [00:15:30] in the genetics of HD in that sense. I can only imagine the kind of stigma that genetic diseases have in general. HD although... that's right. The HD is a prevalently genetic disease. It's also dominant in mostly just genetic... genetic transmitted but the other conditions are mostly idiopathic as they're called in the medical

[inaudible 00:15:59]. So [00:16:00] they sporadically happen in the population. Now, you have some bits... for example, there is around a 10, 15% of cases of ALS for example, that are genetically determined, so those would have similar transmission mechanisms to HD. Now, in terms of stigma, in my experience at least, and this is by no means exhaustive but I haven't found [00:16:30] much in other conditions. So I think that unfortunately it might be more about HD but then again, in a way, I think that HD has that sort of weight on its shoulders because it's born as a genetic condition and it's born as a condition that runs in families. And it's a condition where the cause for... even though [00:17:00] it's always been genetic, we've always had an idea that it was genetic since it was described by George Huntington in the late 19th century.

It was fairly clear that it was a disease that ran in families. We only discovered the gene in 1993... in the early 90s anyways. 1992, I think. So that was fairly recently [00:17:30] in medical terms compared to the history of other diseases. It was just the other day. Even though there has been a massive movement forwards in terms of finding the cure, in terms of trying to silence, for example, the gene and finding some ways to eradicate the disease, it's still very young from that perspective. So it's hard to say really. I think that [00:18:00] nowadays there is more understanding around conditions that are genetically determined and there's... I also think that the psychological aspects have an important role in making these conditions more understood.

So it's not just about reading that some people have a genetic mutation on the long arm of chromosome 4 that causes this kind of... these ganglia [00:18:30] impairments and these sort of neurological symptoms. It's about understanding that there are people with lives, with loved ones and lots of other people around them that are impacted by a condition that is life limiting, that is devastating and creates all sorts of psychological and psycho-social impacts.

Host (Kevin Gre...: Dr. Zarotti, so circling back [00:19:00] to the research that you worked on, who were you hoping to reach with the guidance that came out? Is it intended exclusively for psychologists or is it something that you think will be equally beneficial for other members of what is hopefully a multi-disciplinary care team that the HD patient is connected with?

Dr. Zarotti: Absolutely, the multi-disciplinary care team. We did not write that guidance just for psychologists. We actually made [inaudible 00:19:30] [00:19:30] trying not to... trying to keep it jargon-free. Trying not to make it sound too directed towards psychologists. So we will include, for example, a glossary of psychological therapies and psychological terms at the end of the guidance, specifically because we believe that these kind of conditions, including HD, they're not conditions that are usually dealt with in vacuum. [00:20:00] Not just that they're dealt with by a single clinical figure like maybe a psychiatrist or a psychologist or a neurologist but they're usually managed by a very wide multi-disciplinary team. And it's essential that there is communication with the team,

so we really aimed at providing as much information as possible to as many people [00:20:30] involved with the care of HD as possible.

Host (Kevin Gre...: And how much data, in terms of existing research or studies were available to you for this effort and did you find that work previously done in HD was on par with other disorders or was it much less common?

Dr. Zarotti: Much, much less common. So we actually published our review recently in the Journal of Huntington's Disease. We actually [00:21:00] titled the review specifically, Psychological Interventions for People with Huntington's Disease: A Call to Arms. Specifically, Call to Arms, because there is so little [inaudible 00:21:11] at the moment that we really need a collective effort towards finding the new evidence. So for example, we had... in general we found around, I [00:21:30] think in total something like, I think, 300 citations for all conditions together. HD eventually only had nine studies.

Host (Kevin Gre...: Oh wow. [inaudible 00:21:47].

Dr. Zarotti: So HD was by far the least represented. We only had nine studies included in our review, of which only one was [inaudible 00:21:59] trial [inaudible 00:22:00] [00:22:00] and not even one specifically addressing psychological difficulties, that was mostly addressing aggression. We only found that the studies that emerged from the review only covered a very short range of psychological factors, which included anxiety, depression, apathy, irritability and [00:22:30] coping strategies. As I said, the evidence is very limited. We only found some preliminary evidence for low methodologically valuable studies so that... for example, [inaudible 00:22:50] or pre-post evaluations about cognitive behavioral therapy and the fact that CBT might be helpful [00:23:00] for anxiety or depression. There is some idea that it might also help with improving copying skills but that comes from a few limited qualitative interventions... Sorry, qualitative studies. And there is not much else.

Irritability, there is no investigations specifically on irritability. As I said, we found some evidence around behavioral relaxation, for example, for aggression [00:23:30] but then aggression is only one part of the equation because you have... that's the behavioral part of irritability and you normally also distinguish between aggression and anger. The emotional side is completely neglected, so there's nothing on many other aspects of the literature on HD, in terms of psychological difficulties that we know exist, [00:24:00] for example, obsessive compulsive symptoms, perseverative behaviors, psychotic experiences. There's literally nothing out there yet, psychological interventions for this.

So we really had to take some inspirations, just an inspiration from other conditions. Some of the suggestions we drew from other conditions, especially ALS was for example, using the so-called third wave of [00:24:30] cognitive behavioral therapies or mindfulness derived kinds of therapy like mindfulness-based stress reduction which seems to be showing some promise with ALS but

as I said, it's something that needs a big push in terms of high quality investigations involving high numbers of people with HD. And at the moment we don't have any of that.

Host (Kevin Gre...: I was going to say, so in addition to the recommendations [00:25:00] that also come out of this guidance for Huntington's disease, I assume one of the underlying themes and hopes is that this also drives an increased interest in researching those conditions, right?

Dr. Zarotti: Yeah, yeah. That's why we call the review a Call to Arms because we just want people realize that this is not just... which is obviously the first point, helping people with HD but this is also an opportunity in [00:25:30] research to develop a very underdeveloped part of the research field and we really hope that this call is heard because we need this research. We need to understand these issues better and at the moment it's really sad to see that actually we're talking about, again, people who live 15 to 20 years with this condition. [00:26:00] So it's not something that is going to stay for a short time with them. It's something that is going to accompany them for a very long time and just imagine that they have to go through 20 years of receiving little to no psychological advice or guidance because there is no guidance in the first place. It's really sad.

Host (Kevin Gre...: Absolutely. There is something I wanted to have [00:26:30] you speak on too. In the published guidance I read, there's acknowledgement of the influence of the social model of disability.

Dr. Zarotti: Yes.

Host (Kevin Gre...: Can you explain to our listeners what that is and how it can complicate the delivery of effective psychological support for somebody dealing with HD?

Dr. Zarotti: Yes. Well, that links back to what I was talking about earlier in terms of the predominant framework that has [00:27:00] been characterizing HD in the past 30 to 40 years. So the idea that we mainly looked at HD through the neuropsychiatric lens especially when it comes to psychological difficulties and disabilities for the better part of the past half century. And that means that there's a tendency to ignore all the other aspects that have a massive [00:27:30] influence on what we call disability and what we call psychological difficulties and the inability of people to reach out for support. So the social model of disability takes into consideration all the aspects of society that contribute to creating the notion of disability, which are not only based on neurological [00:28:00] changes. They're based on, as you mentioned, stigma, for example. Based on accessibility for people with motor neurone [inaudible 00:28:09] conditions. For example, if you can't move then you can't access a certain place, then you can't receive support for that. They're based on how we perceive people with certain conditions and how we respond to them.

I always think of one of the patients that I saw for my PhD which really stayed with me as story [00:28:30] because I found it really sad but also a nightmare in terms of highlighting these difficulties. There was this patient that I interviewed and he told me how much he struggled in this little town in the north of England when he was going out and about to do some shopping, to go to the shops and buy groceries. He always had to carry with him a card saying that he was not drunk but that he had HD, [00:29:00] that he had a condition that made him look like he walking drunk in the streets because he would be stopped by the police every so often to check why he was behaving like that and why he was walking in that way and people would stare at him.

And that's probably one of the best examples that you can make of the social [inaudible 00:29:23]. Actually taking for granted that people who will be behaving a certain way are [00:29:30] behaving like that not because they... because they have a condition that actually makes them look like that but then they're absolutely not what we assume they are but we just jump to conclusions and don't offer the support that these people need.

Host (Kevin Gre...: Yeah. I mean, that's not an uncommon occurrence and it's just the power of assumption can be very confining for patients and people in those situations [00:30:00] for sure. Dr. Zarotti, I know you've touched on some of them throughout the course of this conversation but just lumping them together in kind of one fashion here, HD has a challenging number of psychological difficulties associated with it but not everyone maybe fully aware of all of them. What are the most frequent psychological issues that tend to manifest in Huntington's disease?

Dr. Zarotti: [00:30:30] Well, [inaudible 00:30:34] that the two most common would probably be anxiety and depression, and that's again why it's understandable because there's a plethora of factors that can combine to create anxiety and depression. And again, it's not only the changes in the brain, [00:31:00] which of course can have an impact in the genesis of anxiety and depression but also the impact of the diagnosis, the impact of knowing that it runs in the family. We tend to forget that, in a way, HD has this sort of extremely sort of uncommon situation where a person can be born with [00:31:30] the awareness that they are at risk of a deadly disease and they will always have the question whether they have it or not hanging over their head unless they decide to get tested. And actually the literature around testing quite interesting in understanding how people manage this sort of anxiety because very few people, as I'm sure you're aware, actually go for the test in general. At least the last time I checked it was less [00:32:00] than 20% of individuals at risk who decide to get tested and I would say it's quite understandable.

But it's also [inaudible 00:32:08], if you get tested and you get a positive result then [inaudible 00:32:12] tell you when the disease is going to start, when the onset will be. So you'll basically know that you have this sentence of having the condition at some point in your life and will ultimately die with the condition

[00:32:30] but not knowing when the condition will start. So for example, there is now some literature arising around some symptoms or anxiety emerging in people who have tested positive but haven't started showing motor symptoms and there's so-called symptom watching phenomena where people with a positive test for HD start ruminating and worrying all the time about the symptoms of the HD starting out. [00:33:00] They might actually confuse symptoms of anxiety with the onset of HD. And then obviously has all sorts of complications in terms of psychological well-being, in terms of interpersonal relationships.

And then yes, interpersonal relationships as well at large, if you think all the other aspects involved with having a disease that is [00:33:30] running in families, that has a 50% chance of being transmitted to children and then people with big families would have children who will inherit the disease and children who don't. I mean, we can only imagine what sort of very difficult dynamics can go on in families where statistically half of the children will inherit a condition and the other half [00:34:00] won't. The guilt felt by those who don't, the depression and anxiety of those who did feeling like, "Why me?" Their parents feeling guilty for having given that to their children. So anxiety and depression in that sense absolutely understandable at any level. But as I said, it's very sad that despite this awareness, [00:34:30] we know that, we've been knowing this for a very long time, we've known this for quite a long time by now, there hasn't been any efforts of trying to find psychological interventions to address them.

Host (Kevin Gre...: So dovetailing off of that, did your research target any specific aspects of HD or was it more broad in nature? So for example, were you looking at adult-onset versus juvenile-onset or manifest versus pre-manifest, or [00:35:00] like you said, even at-risk versus somebody who knows they're gene positive?

Dr. Zarotti: So in terms of the guidance we focused on adult-onset, both pre-manifest or manifest. Well, the manifest bit is also something that I feel very strongly about in terms of what we mean by manifest and that's something that I believe should receive further [00:35:30] attention in the future as well. With renewed information from the psychological literature because we know by now that HD doesn't start with motor symptoms. We know that cognitive impairment, behavioral and psychological difficulties, emotional difficulties precede motor symptoms by years at times, [00:36:00] even decades at times, and yet the diagnostic criteria for HD so far have only been based on motor symptoms. So if people don't have motor symptoms yet they're not diagnosed with HD and we're referring to them as pre-manifest but it makes you wonder, to what point does it actually make sense to call these individuals pre-manifest if they've been struggling with psychological or [00:36:30] emotional or cognitive difficulties for years already?

So in that sense, we focused on... we didn't really cover juvenile but that was mostly because all the other conditions don't really have juvenile [inaudible

00:36:46]. We talk of young-onset Parkinson's but it's different, very different from HD because young-onset Parkinson's is considered before 50 while juvenile HD is before 20 so they're very different age groups but [00:37:00] I would say that apart from not having focused on juvenile... and I think for juvenile there's quite a lot of research going on at the moment from the Italian League, Ferdinando Squitieri [inaudible 00:37:15] who also have contributed some... I collaborated with for some of my studies in my PhD and they've been doing quite some amazing work with people with juvenile HD. We mostly focused [00:37:30] on adult-onset HD. But then again, where we draw the line between manifest, pre-manifest, at-risk... I mean, at-risk we know it because it depends on whether there's a test or not but manifest or pre-manifest, that's something that really needs to be brought back into discussion in my opinion.

Speaker 1: We'll return to the interview on the HD Insights Podcast in a moment. We hope [00:38:00] that you're enjoying this episode. As a nonprofit organization, the Huntington's Study Group relies on the generous support from the community and listeners like you to continue bringing you in-depth content on HD, like this podcast series. If you like what you're hearing and are interested in supporting HD Insights through a grant or donation, please contact us through our email address, info@hsglimited.org, or by calling [00:38:30] toll free at 1-800-487-7671. We greatly appreciate your support. And now, back to our episode.

Host (Kevin Gre...: There were several recommendations, total recommendations about psychological interventions in HD from the research. Can you talk about those and their importance to the overall care [00:39:00] someone with HD may need?

Dr. Zarotti: Yeah, sure. Well, as I said, we actually weren't in the position to make a lot of suggestions for people with HD unfortunately because of the lack of literature. Now, in terms of what we can say at the moment is that [00:39:30] when there is some general issues around anxiety and depression we can sort of follow the guidance for... that had been produced already by organizations for people with chronic conditions because to a certain extent they can still help because people with HD are people who are suffering from a chronic condition, so some of the aspects might be helpful. For example, in the UK we have the NICE guidance for [00:40:00] depression in individuals with chronic conditions that can be used as an inspiration. I'm sure that you have some equivalent in the US as well. And then when it comes to specific, some HD specific symptoms then as I said, we don't really have much evidence. We might try to look at... one of the suggestions would be to look at the guidance made around symptoms [00:40:30] per se, so for example, irritability.

Irritability is very specific for HD when it comes to motor neurone degenerative conditions but there is quite a florid literature around irritability in general, [inaudible 00:40:46] difficulties in people in general. So that might be feasible in terms of getting the first idea of what to do intervention-wise. Then again, there [00:41:00] is nothing specific and most... The most important suggestion that we

can do at the moment is to promote research, to promote new evidence. So obviously people will have to... especially professionals, will have to deal with this condition from [inaudible 00:41:26] clinical practice and as I said, well, I would [00:41:30] suggest referring to specific guidance from specific symptoms when they're HD specific, like irritability or apathy and then general guidance for more generalized difficulties like depression and anxiety. But what we really need to do is pushing this need forwards and making it heard by the community. Making it heard by not only researchers but [00:42:00] by policy makers, the government, making them understand that there is a lot of people out there still suffering from this condition that are receiving no support at the moment.

Host (Kevin Gre...: Yeah. and hopefully even through this podcast we can help emphasize that call to arms that you referred to. I'm curious, what do you think the future holds for doing a better job of mainstreaming psychological care [00:42:30] for HD patients and what do you think are the biggest barriers that right now are currently preventing that?

Dr. Zarotti: Well, what we found in the UK, for example, is that the access to psychological services for people with HD across the United Kingdom tends to be very [inaudible 00:42:50] unequal and there're very few services that specialize in these conditions. Now, the problem with conditions like Huntington's is that it requires [00:43:00] quite a lot of specific knowledge to be dealt with. So it's not a condition that you can just send an individual to a generic psychological support service expecting them to know how to deal with it because there's so many factors contributing to these psychological difficulties that people with HD are not best [00:43:30] served by generic psychological wellbeing services. And that's probably the biggest barrier because given that there're no or very little or very few specific HD services when people with HD try to access more generalized psychological wellbeing services they get stuck.

Either they fall through the cracks in the system or [00:44:00] they even get bounced back because they're considered sometimes too severe in a way [inaudible 00:44:07] for those services. So that's one of the biggest barriers, I believe. Trying to... we need, in the future to create more specialized services that can account for the other complexity of people, not just with HD but with these conditions. [inaudible 00:44:27] I think that actually bringing these conditions together [00:44:30] will help in terms of creating services that are cost effective because we have to consider also that when it comes to policy makers, when it comes to the government, that there is also an economic aspect of it. So obviously doing just services for HD might be not that cost-effective because unfortunately... well, fortunately in a way, HD is not that frequent but unfortunately that doesn't help people with HD.

[00:45:00] But if we do push the idea that we can create centers, specialized in conditions that have similar features like HD, Parkinson's, ALS, multiple sclerosis, and then those services can specialize in providing specialized

psychological services and wellbeing services, and addressing even difficulties at a social level [00:45:30] then that will become even more cost-effective, because we also have to consider that whenever someone doesn't receive some care from a psychological perspective then that cost is not avoided from a government point of view. They end up being cared for for other difficulties. They either get cared for in terms of pharmacological terms or... [00:46:00] The bill gets back to society some other way. So it's not that by not taking care of the psychological difficulties of people with HD, we're avoiding the cost. We're actually just hiding it under the carpet and it's going to resurface in another way and by promoting specialized services, I believe, it would be a great way for society to actually address these issues in a cost effective way and first of all, address these [00:46:30] issues that make quality of life for people with HD much better.

Host (Kevin Gre...: Yeah. That's a really fascinating idea, kind of leveraging the synergies from those other diseases and conditions. I'm curious, actually it makes me think back to one other topic we kind of covered which was the fact that those other conditions also have a lot of well-known, I guess, ambassadors or people that have dealt with it or are currently dealing with those conditions. I want to ask you this, [00:47:00] in our current environment with COVID-19 pandemic, that has certainly brought to light psychological concerns for the general population to the forefront, do you think that our experience coming out of that could actually be a silver lining for emphasizing the importance of providing greater access to psychological services for people with HD?

Dr. Zarotti: [00:47:30] Well, I certainly hope so. You're right. There has been quite a spike in psychological difficulties, not just in people with HD but in general because lockdown has hit us all... I think all of us very hard. The problem, I would say, is that people with HD in general, people with neurodegenerative conditions or people with serious health concerns [00:48:00] tend to be at the outskirts of society when a crisis happens because the most vulnerable part of society tend to be forgotten, I would say, when a crisis happens. So people who already were quite vulnerable before because, for example, they had HD, then become even more vulnerable during a global pandemic and sadly even more forgotten because of the isolation that comes with a global pandemic, [00:48:30] with lockdowns. And just imagine all the people with HD who maybe be living on their own and all the added difficulties having a global pandemic may add on top of their condition, and accessing medication, and accessing medical, psychological, social support.

So in a way, I hope, as you say, that the silver lining might be a renewed interest in psychological support. Although I think that [00:49:00] that might be more of a general tendency, so there is a bit of an awakening at the moment with society saying, yeah, before this is gone, "We'll... even before this is gone and not just after the pandemic, we'll have to start dealing with all the psychological consequences of the pandemic." What I really hope and I think that that's something that we need to fight for, we need to monitor, is that this is not

[00:49:30] just about generalized services again, but also services for people who already have health concerns, like people with HD, because this is not just about providing the support which is needed obviously for the people who started having psychological difficulties because of the pandemic but also the people who [inaudible 00:49:53]... There're already present psychological difficulties incredibly worsened by [00:50:00] a global pandemic and that includes people with HD.

So I'm hopeful but I think we need, as a community, helping the people with these conditions to make their voice heard because, as I said, I think there is tendency in society to forget about the people that were struggling already before a crisis and we need [00:50:30] to realize that what for us was a crisis that happened all of a sudden, for other people was just the umpteenth issue to deal with on a regular basis.

Host (Kevin Gre...: Well, Dr. Zarotti this has been fascinating chatting with you about the research and I want to make sure we leave enough time that I can talk to you about your personal background, but I would be remiss if I didn't give you the opportunity to acknowledge anyone else, any other colleagues or...

Dr. Zarotti: Yes.

Host (Kevin Gre...: ... [00:51:00] people that were involved in this.

Dr. Zarotti: Yes, absolutely. First of all, my colleagues at Lancaster University, Professor Jane Simpson who's a professor of actually the psychological of neurodegenerative disease, so she dedicated her whole lifework to developing resources for people with these conditions. And then Dr. Fiona Eccles who [inaudible 00:51:26] guidance with me as well. And [00:51:30] then there's been quite a few other professionals that have helped us for the guidance in general. There're probably too many to mention all but for HD, I'd be happy to mention Dr. Maria Dale from the Leicestershire Partnership at NHS Trust that is actually working in one of the very few HD specialists services in the UK. They're doing some amazing work.

That said, [00:52:00] it's... I also wanted to knowledge the HSG in general. I've been involved with the HSG since I started studying for my PhD seven years ago by now. And I think the HSG is doing a great job in promoting awareness for HD, in promoting the drive to find a cure but also being sensitive to the [00:52:30] need for psychological difficulties. I really enjoyed coming to the HSG meetings when they were still in person, at least

Host (Kevin Gre...: Right. Yeah.

Dr. Zarotti: Yeah. I was lucky enough to be able to attend the last one [inaudible 00:52:49] because I was awarded the Peter Como Scholarship which is specific for psychological aspects of HD. And I think that [00:53:00] having a scholarship

that is specifically aimed at psychological professionals is amazing. This really shows how HSG is ahead of its time in terms of promoting aspects that tend to be neglected, not just in HD but these sort of psychological... Sorry, these sort of neurological conditions. So absolutely, I actually hope to bring the review [00:53:30] on psychological interventions to the next HSG meeting if it's going to be in person. I really hope it will. Fingers-crossed. But yeah, I really want to acknowledge HSG in that sense because it's being incredibly helpful, not just in terms of the work done around people with HD but those [inaudible 00:53:53] supporting researchers like myself working with HD.

Host (Kevin Gre...: Well, [00:54:00] let's talk now about yourself and your work. Specifically, I'd like to hear about your journey into psychological. I know you're originally from Italy, even though currently you're living and working in the United Kingdom. What was it that got you interested in this field and led you to where you're today?

Dr. Zarotti: Well, I've always been interested in neurological conditions and the psychological impact they can have. I have a [00:54:30] background in neuropsychology, mostly in terms of my first studies in Italy. And I ended up coming to the UK to do a PhD, as I said, on Huntington's because I found that the literature was so poor already back then still that it really needed more than what was available. [00:55:00] So when I started, I would say, probably we had half of the results we found so far in the review that we published so, I would say, probably just in the last five to seven years there has been some bit of awakening in that sense. And none of those citations that we found in terms of interventions were produced by us so at least we know that it's not our work that has [00:55:30] produced that. It's more a widespread interest. But I believe that it's... as I said, it was very fascinating in a way, but also very saddening to see that there was little to no evidence on psychological approaches to HD. And I think that there is still so much room for improvement.

So even though at the moment I'm not working full- [00:56:00] time in research because I did my PhD at the Lancaster University in the UK then I moved on to the University of Sheffield for a year to do a postdoc on ALS and at the moment I'm actually training in clinical psychology, which is sort of the equivalence of the American PsyD at the University of East Anglia. And I'm focusing more at the moment more on Parkinson's disease for my current thesis but [00:56:30] I'm always holding HD very dear to myself because I really think that among all these conditions, HD is the one that has the biggest room for improvement and drawing inspiration from other conditions like Parkinson's... Parkinson's I think is one of the most prolific communities at the moment in terms of research and there is so much that we can learn and apply from the Parkinson's community on to [00:57:00] the HD community.

I believe that... as you mentioned, there is a need to create this synergy between different conditions which have common features and definitely my aims for the future at the moment are to continue doing clinical research once I

qualify as a clinical psychologist, trying to bring together these conditions and allow them to inspire each other [00:57:30] in a way. I think there's strength in unity there much more than there is in separation.

Host (Kevin Gre...: Absolutely. Is there anyone in particular that you really consider a role model or a mentor, someone that's particularly inspired you in your academic pursuits?

Dr. Zarotti: That's an interesting question. Well, I've met many [00:58:00] very inspiring academics. Definitely my PhD supervisor, Professor Jane Simpson. She's been a great inspiration for psychological aspects of motor neurone degenerative conditions and neurodegenerative conditions in general for that matter. When it comes research [inaudible 00:58:24] finding a cure or actually doing more medical research, as I mentioned [00:58:30] already, Ferdinando Squitieri from the Italian League for Huntington's Research. He's absolutely outstanding in the way he carries on doing research even during the pandemic like this. So he's definitely been a role model for the effort that he's been doing for the HD [00:59:00] community. But then again, I would say that the HSG community as a whole.

I don't think I have one person that I can pinpoint as my role model. I think that the HG community itself has been an incredible source of inspiration in that sense. And if we consider that I started my PhD with Huntington's... I did my PhD on Huntington's, so I didn't do a PhD on a very well-known condition that has a lot of [00:59:30] awareness already going on like Parkinson's, like I don't know, other conditions like Alzheimer's or a more common condition like Alzheimer's but it was more of a, as I said, a lesser know condition with yet very, very keen clinical research and patient-based community that has been absolutely inspiring.

Host (Kevin Gre...: [01:00:00] I want to go a little off topic here and ask you about something. So people that may follow you on Instagram will probably notice a lot of really stunning photos of the cities that you're in. Is photography a hobby or is it just more about capturing, sharing the beauty of those places and their architecture? I'm just curious because I tend to notice when they come through on my scroll that they are just stunning to look at.

Dr. Zarotti: [01:00:30] Thank you. Well, at the moment my Instagram profile is private at the moment because of the clinical training and as a policy but thank you again. I really like photography. I'm an [inaudible 01:00:46]. I'm not a professional photographer by any stretch of your imagination but I think that in a way [01:01:00] that's been an evolution of how I moved... when I moved from Italy to the UK, in a sense that when I was in Italy I really enjoyed writing fiction, nonfiction, especially fiction back then but then when I moved to the UK, well, I sort of had to start off again when it came to language because obviously English is not my first language and [01:01:30] especially with the first time I moved to the UK, I felt like I wasn't myself anymore because I couldn't express myself the same way I would do in Italian.

It was quite an interesting yet tough moment to go through, I have to say, because it really makes you aware of the impact of language on your identity. But that said, I probably switched to photography in that sense because photography speaks every language. [01:02:00] So the sort of creative strain that I had in writing at that time I just moved it to... I switched to the visual language of photography so that's where I sort of developed an interest. And then I carried on even though I probably now can feel a bit more confident in terms of writing in English as well, but I just picked up the passion for it and I really like it.

Host (Kevin Gre...: Well, you do a great job. The ones that I have seen have definitely piqued [01:02:30] my interest in terms of places that I want to visit in the when [crosstalk 01:02:35] traveling becomes an option again, I guess.

Dr. Zarotti: Yeah. I can definitely recommend England. There's some beautiful place... Just remember to bring an umbrella but there's some beautiful landscapes and sunsets that you can find here. And I really want to come back to the US as well. Actually the only times I've been to the US so far has been for the HSG meetings so I've seen... I'm really glad [01:03:00] in a way because I've seen places that people normally wouldn't visit. If you go to do some mainstream US tours you go to New York, Los Angeles, or Chicago, Washington. You wouldn't really go to Tampa or Denver or Houston. And I'm really glad I did because it allowed me to see so many characteristic places, that I [01:03:30] mean, they're not something that you would see in the most touristic places in the US so it's been fascinating in that sense.

Host (Kevin Gre...: Yeah, absolutely. I just want to wrap us with one more question for you and that's, is there somewhere people can go to learn more about this particular research that we've talked about today? I know you've mentioned the Journal of Huntington's Disease. Any other HD research or other research that you're involved in?

Dr. Zarotti: Well, they can find my page on Google Scholar, so if they type my [01:04:00] name on Google Scholar they will find all my publications there. When it comes to the guidance itself, the guidance is available for free... to download for free from the British Psychological Society and I will be giving you the link so that you can sign post it in the description of this episode of the podcast, if you want, so that they can download the guidance for free. And yeah, I would also [01:04:30] recommend absolutely looking up the research done by Dr. Fiona Eccles and Professor Jane Simpson especially since they've been active far more than me... for far longer than me so there's much more to learn from them than me, in the first place.

Host (Kevin Gre...: Well, we appreciate it Dr. Zarotti. I greatly thank you for your time today. It's been a fascinating conversation about the psychological aspects [01:05:00] in the research that you're doing in HD and wish you all the best on your continued endeavors.

Dr. Zarotti: Thank you very much. It's been amazing to be hosted here. Thanks again for all the great work you're doing for researches on HD worldwide.

Host (Kevin Gre...: Thank you again for listening to this episode. I once again would like to extend my thanks to Dr. Zarotti for his time in helping to call attention to the critical [01:05:30] need regarding further research and focus on psychological interventions in Huntington's disease. If you would like to read the published guidance from the British Psychological Society or learn more about Dr. Zarotti's research you'll find a link to both included in the description for this podcast episode. Until next time, thank you for listening to the HD Insights Podcast. Stay safe. Be well and take care.

Speaker 1: We hope you enjoyed [01:06:00] this edition of the HD Insights Podcast. Remember to subscribe to this podcast to make sure you automatically get the latest episodes to your device. Please rate and review this podcast with your feedback so we can continue providing the best possible content. If you are interested in providing financial support for the work needed to produce this content, you can do so by becoming an ongoing sponsor or through a tax deductible donation. [01:06:30] To do so, please email us at info@hsglimited.org. That's I-N-F-O @ H-S-G limited.org, or by calling our toll free number at 1-800-487-7671. Thank you for joining us on the HD Insights Podcast from the Huntington's Study Group.