The GRACE Project
Genetics and the Gypsy, Roma, Traveller community

Lisa Robinson:

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Did you know that there are between 10-12 million Roma people currently living in Europe? That makes us one of Europe's largest ethnic minorities, but despite this, we remain one of the most misunderstood and misrepresented groups.

Hi, my name's Lisa Robinson, and as well as working for the GRACE project I am one of approximately one thousand students of Gypsy Roma Traveller heritage currently studying at a UK university.

In this video I'm going to give you a very brief introduction to my community, the health inequalities we face, how the eugenics movement has impacted us, and how researchers and healthcare providers can be more culturally sensitive and accessible.

An introduction to the community

In the UK the Gypsy Roma Traveller community is made up of ethnic and non-ethnic travellers.

Ethnic travellers include Irish and Scottish Travellers, English and Welsh Romany Gypsies- that's me, and European Roma communities.

Non-ethnic travellers include travelling showmen, new age travellers and boat dwellers. However, it's important to remember that these identities are not fixed distinct entities. For example, there has been inter-marriage between Romany Gypsies and Scottish and Irish Travellers, and many travelling showmen have Romany heritage.

Despite traditionally leading a nomadic lifestyle the majority of ethnic travellers now live in bricks and mortar houses; however, we still maintain a strong cultural identity and uphold many traditions, particularly those surrounding birth, death, marriage, cleanliness and spirituality.

Many English and Welsh Romany Gypsies and European Roma communities believe in the concept of things being spiritually or ritually impure or unclean. For example, health is considered an unclean topic for discussion, so it is often kept as a very private matter. And I'll get into that more a bit later when we discuss issues surrounding access to health care.

Genetic conditions and the community

There are a number of genetic conditions that are more common in the Gypsy Roma Traveller community than in the general population. Among some European Roma communities there is an increased incidence in a number of Mendelian disorders.

These are inherited genetic disorders and are either dominant or recessive in nature. With dominant disorders you only need to inherit one copy of a faulty gene from either your mother or father in order to get the disease, and they will most likely have the condition themselves. In recessive conditions if you only inherit one copy of the faulty gene from one of your parents then you don't have the disorder yourself, but you are a carrier of the faulty gene and could pass it on to your children. If you inherit two copies of the faulty gene, one from your father and one from your mother then you will have the disorder.

Among certain European Roma communities carrier rates are 5-15% for some disorders, and within the Irish Traveller community 104 inherited disorders have been catalogued, and 9% of Irish Traveller parents have a child with a genetic metabolic disorder.

Classical galactosemia is an inherited recessive disorder where the body cannot make enough of the enzyme that breaks down galactose, one of the main sugars found in breast milk and cow's milk. If it's not recognised then galactose can build up in babies' bodies and become toxic, potentially leading to liver damage or meningitis; in rare cases it can even be fatal. It has an incidence of around 1 in 450 births in the Irish Traveller population, compared to 1 in 36,000 births in the general population.

While the increased incidence, and seriousness of genetic conditions affecting the Gypsy Roma Traveller community is sufficient to warrant carrier testing, newborn screening, and community-based education programs, none of these are currently offered to Gypsy Roma Traveller communities in the UK.

A demonstration

But why are genetic conditions more common in the Gypsy Roma Traveller community than in the general population?

Well to answer that, we're going to use this bag of M&Ms to illustrate the impact history has had on the genetics of the Roma people

The Roma originated in India, but left there in around the 9th century, before arriving in Europe in the 12th century, and spread throughout Europe by around the 16th century.

This big bag of M&Ms with all its different colours, represents the genetic diversity of the whole Roma population when they left India almost a thousand years ago.

However, over time, during their migration across Europe the population became fractured, due to things like Gypsy expulsion laws that meant communities had to be constantly on the move, and often had to split into small groups in order to subsist as labourers, entertainers or blacksmiths.

These smaller groups of M&Ms represent these smaller groups of Romani people that were scattered throughout Europe. Let's take a look at one of these groups that has a disproportionately high number of green M&Ms.

We can imagine that these green M&Ms represent a particular gene variant. This gene could be for something completely harmless, like the ability to roll your tongue, in which case, the future generations of this group will include a disproportionately high percentage of people who can roll their tongue. This is known as genetic drift, where due to shifts in population, a particular population by chance ends up with a disproportionately high or low number of a particular gene.

However, these green M&Ms could represent what we call a pathogenic genetic mutation, meaning that if you have this gene, you could either have a genetic condition yourself, or be a carrier for a condition. These are known as founder mutations, where the founders of a particular group have a disproportionate number of genetic mutations. In that case, the future generations of this group would then have a disproportionately high number of people suffering from the genetic condition linked to that particular mutation.

This phenomenon does not only affect the Roma population; we see a similar effect in Irish Travellers and Ashkenazi Jews.

But why is it important to understand where the higher incidence of these genetic mutations come from?

It's important to understand that the increased incidence of genetic conditions in our community is not due to some inherent deficit or inferiority, rather it is evidence of the profound impact centuries of prejudice and discrimination can have on a community.

Eugenics

So, in that vein we're now going to take a look at the impact the eugenics movement had on the Romani people.

Since their arrival in Europe the Roma have been outlawed, enslaved, tortured, and murdered, but in the late 19th century racism that had existed for centuries began cloaking itself in pseudoscience and the eugenics movement was born.

In a nutshell, the eugenics ideology had the belief that humanity can be improved through selective breeding, and to achieve that, inferior elements in society should be eradicated through social exclusion, forced sterilisation, and even genocide.

The most infamous example of eugenics in action is undoubtedly the Holocaust, in which 50% of Europe's Roma population were murdered and many others were imprisoned, forcibly sterilised and used in medical experiments. We call this the Porajmos, the devouring.

But this story doesn't end in 1945 at the end of World War II. For the European Roma persecutions and discriminations have persisted throughout the 20th century and to the present day.

Systemic discrimination through the 20th and 21st centuries

In the latter half of the twentieth century thousands of Roma women across Europe were forcibly sterilised due to the belief that they were a culturally substandard social disease. This practice continued until 2007.

To this day the European Roma are often forced to live in segregated ghettos and their children are subject to educational segregation, with 65% of Slovakian Roma children attending Roma-only schools.

Why is it so important for researchers and health care professionals to be aware of this? One of the key barriers to including Roma in research and healthcare is the distrust in state institutions. It's important to understand that this mistrust is well founded.

For the Roma, what the Nazis started with jackboots and gas chambers, the governments of Europe continued with lab coats and scalpels.

The first step in building trust is in acknowledging this and validating those very legitimate fears.

While the UK government has been more tolerant to the Roma than those of Central Europe, it's important not to sit complacent, as the systemic challenges and inequalities still faced by the Gypsy Roma Traveller community are very real.

The reasons for these inequalities are complex and include factors like deprivation, lack of adequate accommodation, and the complex and often inaccessible healthcare service.

Health inequalities

The Gypsy Roma Traveller community faces some of the poorest outcomes in areas such as health and education. Life expectancy is between 10 and 12 years lower than the general population, and 10% of Irish Traveller children do not live to see their second birthday.

While the majority of the community now live in bricks and mortar houses, for nomadic people a chronic shortage of stopping sites means that 10,000 Gypsy Traveller people are forced to live roadside, and 3000 families lack access to the most basic amenities including safe water.

Nomadic people in particular are often excluded from primary care services as GP surgeries refuse to allow them to register due to not having proof of address, despite the fact that this is not a requirement for registration. However, even for those that live in bricks and mortar houses,

issues like digital exclusion, a lack of accessible information, cultural and language barriers, and fear of prejudice all present significant barriers to accessing health care.

For example, a majority of European Roma communities in the UK speak a dialect of Romanes as their first language, the language of their European country of origin as a second language, and English as a third language, with varying degrees of fluency. Even in the rare cases where a Romanes translator is available, many Roma people will be afraid to disclose their ethnicity or that Romanes is their first language due to fear of discrimination. This means that communication often has to take place in their second or third language, which obviously can lead to misunderstandings and misinterpretations, especially when discussing complex medical terminology.

Additionally, as mentioned before, health may be considered an unclean topic and held as a deeply private matter. Therefore, it could be seen as taboo to discuss health with someone of a different gender, or someone with whom there is a significant age gap.

But there are things that we can all do to improve this picture.

How to engage

As a researcher or a healthcare provider one of the best things you can do is reach out to the community, or third sector organisations. Public involvement is essential to ensure that research is relevant to our community and that services are accessible. There are some fantastic national and local organisations including: Friends Families and Travellers, The Roma Support Group, The Traveller Movement, Herts GATE, and the Romani Cultural and Arts company.

These organisations can also provide cultural competency training that will make your research techniques and services more acceptable, and help your team overcome any unconscious biases.

And finally, acknowledge the past, recognise that the anxiety and mistrust surrounding health services are understandable and steeped in a thousand years of history.

To find out more, please read our framework for engaging with the community. And thank you for watching.