Short Communication
Volume 9:3, 2020
DOI: 10.37421/jtm.2020.9.456

Journal of Trauma & Treatment

ISSN: 2167-1222 Open Access

The Most Effective Method to Instruct Others about your uncommon illness

Shima L*

Ataxia Unit, Massachusetts General, Boston

Abstract

Rare diseases have taken a toll on the health of patients and their families mostly contributing to the shallow knowledge in order to explain the complexity of the situation to the physician; thereby ending up in late diagnosis and misdiagnosis. The aim of this study was to report the training needs in the general public health system within the diagnosis, treatment and monitoring of patients with rare diseases and to create awareness so as to make a better place for such uncommon ailments.

Keywords: Disease • Public health • Clinical complexity

Introduction

My husband has 2 rare diseases. Ataxi who? ataxi what? Mitochondri? Where do I get information? Google? Been there done that and as I'm sure you can relate it was very overwhelming and scary and worse than that I wasn't sure it was even reputable. Honestly, it scared me to death. It was so technical. I needed a PhD to understand it and I didn't have that kind of time. I needed the information now, not in 10 years from now when I got my doctorate and to boot family, friends, acquaintances and complete strangers were all looking to me to explain it. They just didn't get it. Heck, I didn't even get it. You know that glazed over look when you start to explain what 'quote-unquote' is wrong with you. You better be prepared for the cliff notes version. Anything longer than 2 sentences and now they're experiencing a brain freeze [1]. This is what got me thinking about finding a better way. I wanted to be heard. I wanted them to understand. My experience as a corporate trainer told me I had about 30 to 60 seconds to get my point across. In that amount of time, I could give them a kiss. A 'Keep it simple stupid' kiss. Step 1: Ditch the medical terms. Step 2: create a mental picture using descriptive words. Let me show u what I mean, we're going to play a visualization game. Can everyone look down or close your eyes picture a zebra. Do you have a mental image in your mind? How would you describe the zebra? What colors do you see? How many legs does it have? Picture a red delicious apple. What shape is it? Or what about a can of Coca-Cola? How about a stop sign? Or a traffic light? Think about the words you would use to describe these pictures. Zebra has 4 legs and is white and black [2]. The apple is oblong. Coke can is red with white lettering. Stop sign is a red hexagon. Stoplight has three colored circles, one red, and one yellow, one green. Ok, you can look up or open your eyes now. Does this make sense? Be as descriptive as possible so people can see what you're describing and not get lost in the words! It really does help people understand. It takes some thought but the beauty of it is, its re-useable. Once you've determined the words to use you can create a descriptive elevator speech that you use every time someone asks about your condition. You are the expert. Like it or not you are both the person with the disease and the spokesperson for that disease. You have to educate everyone you come in contact with including your doctors. I don't know about you but that makes me feel pretty smart. Oh, and another responsibility I take on is correcting the misinformation someone has about the disease. Like when someone thinks you???re going to get better. Like you get better from a cold. Or that you can fix it with medication [3]. Or how about when they think you're better or not progressing because 'you look good'. I often hear that one. John looks great! He must be doing better. Ever hear that? I often wonder 'how are you supposed to look?' It goes back to that mental picture in your head. People think you have to look a certain way when you have a rare disease. They can't wrap their head around the fact that it might not be visually obvious [4]. And that can be the hardest part and the main reason why it's important to explain your condition as visually as possible. I would challenge you to think differently. Change your perspective. Be your own advocate. Develop a comfort level with sharing what you are experiencing with others. You can be empowering and change the stereotypes. As we say in Boston. Do your job. And your job is to spread awareness about your rare disease [5].

There are 350 million patients with a rare disease globally. Within the US alone there are 30 million people with rare diseases. On the continent of Europe, there are 30 million people with a rare disease. We seek to possess a worldwide outreach in order that we will help as many rare disease patients as possible. Many rare disease patients suffer for several years, and a few even die without a conclusive diagnosis. Even after they receive a diagnosis, many patients with rare diseases don't have access to a treatment that's effective [6]. For many of them, the look for effective new treatments continues for a really while. Does one have a rare disease? What if we could offer you information that might lead you to a conclusive diagnosis, or maybe a treatment or a far better treatment? We believe that might make a difference to your life. Rare diseases are a priority objective of public health care systems. Given its complexity, late and misdiagnoses occurs fairly often which causes mental and physical burden for patients and family. This is able to be caused, in part, for unprepared clinicians during this field [7,8]. The aim of this study was to report the training needs and therefore the perceived shortcomings of Spanish physicians of the general public health system within the diagnosis, treatment and monitoring of patients with rare diseases. These diseases are a crucial challenge that affects public health, the event of latest diagnostic methods and therapies, and therefore the clinical, social and health care that these patients require [9,10].

Conclusion

A recurrent concern of those patients and their families is that the limited knowledge that physicians have about it thanks to the high clinical complexity, which ends up in late diagnosis and misdiagnosis. The typical time between the onset of symptoms and therefore the diagnosis of a patient with a rare disease has been estimated to be on the brink of 6 years, while within the pediatric age it's longer than 15 months. These examples are often frustrating for both health professionals and patients

***Address for Correspondence:** Shima L, Ataxia Unit, Massachusetts General, Boston, Tel: +16177262000; E-mail: shimal@msn.com*

Received 22 June, 2020; **Accepted** 24 July, 2020; **Published** 31 July, 2020

References

1. Boycott Kym, Megan Res, Vanstone Dennis and Alex E. MacKenzie, et al. "Rare-disease genetics in the era of next-generation sequencing: discovery to translation." *Nature Reviews Genetics* 10 (2013): 681-691.
2. Griggs Robert C, Mark Batshaw, Mary Dunkle and Rashmi Gopal-Srivastava, et al. "Clinical research for rare disease: opportunities, challenges, and solutions." *Molecular genetics and metabolism* 1 (2009): 20-26.
3. Castillo-Esparcia Antonio, and Paloma López-Villafranca. "Communication strategies employed by rare disease patient organizations in Spain." *Ciência & Saúde Coletiva* 21 (2016): 2423-2436.
4. Mogul Douglas B, Macey L. Henderson, and John FP Bridges. "Expanding the facebook platform to engage and educate online communities." *American Journal of Gastroenterology* 4 (2018): 457-458.
5. Wood Jill, Lori Sames, Allison Moore, and Sean Ekins. "Multifaceted roles of ultra-rare and rare disease patients/parents in drug discovery." *Drug discovery today* 18 (2013): 1043-1051.
6. Austin Christopher P, Christine M. Cutillo, Lilian PL Lau and Anneliene H. Jonker, et al. "Future of rare diseases research 2017–2027: an IRDiRC perspective." *Clinical and translational science* 1 (2018): 21.
7. Zurynski Yvonne, Katie Frith, Helen Leonard and E. Elliott. "Rare childhood diseases: how should we respond?." *Archives of disease in childhood* 12 (2008): 1071-1074.
8. Gaskell Jr, P. C, and Jeffery M. Vance. "Alzheimer's disease genes and genetic testing in clinical practice: to educate patients, PAs must understand the genetic heterogeneity of AD and be able to discuss both genetic testing and the implications of test results." *JAAPA-Journal of the American Academy of Physicians Assistants* 3 (2004): 25-30.
9. MacLeod Haley, Kim Oakes, Danika Geisler and Kay Connelly, et al. "Rare world: Towards technology for rare diseases." In *Proceedings of the 33rd Annual ACM Conference on human factors in computing systems* 1145-1154. 2015.
10. Budych Karolina, Thomas M. Helms, and Carsten Schultz. "How do patients with rare diseases experience the medical encounter? Exploring role behavior and its impact on patient–physician interaction." *Health policy* 105 (2012): 154-164.

How to cite this article: Shima L. "The Most Effective Method to Instruct Others about your uncommon illness." J Trauma Treat 9 (2020): 456 doi: 10.37421/jtm.2020.9.456