

**Background:** According to the Canadian Organization of Rare Diseases (CORD), 1 in 12 Canadians has a rare disease: that's over 3 million Canadian citizens. Despite this high number, our rare disease patients are suffering every single day in our lacking healthcare system, and the existing literature on the topic is scarce. My research sought to understand the diagnosis process as it is experienced by women in Canada living with rare, invisible, physical chronic illnesses. Age, gender, the invisibility of an illness, and the rareness of an illness were examined to understand their influence (individually and combined) on the diagnostic experience. Existing research has not examined these intersections, and little research has been conducted within a Canadian context.

**Methods:** I conducted 20 structured interviews over email with women who were split into two cohorts: 10 women were aged 18-30 who were diagnosed within that age range, and 10 women were over 30 years of age who were diagnosed within the last 12 years. These women answered 20 questions regarding their experiences getting diagnosed with rare, invisible, physical chronic illnesses. Their answers described their personal experience with the process of diagnosis, their most positive and negative experiences with the healthcare system, how they felt different aspects like age and rareness impacted their experiences, and what they would like to see done differently. The study was conducted within the theoretical frameworks of feminist disability studies and critical disability studies, and was approached from an autoethnographic standpoint, having myself lived through the same general experience as these women.

**Results:** The interviews revealed common experiences of trauma, neglect, negligence, dismissal, and misdiagnoses among majority of the participants. Twelve participants reported having to change doctors due to negative experiences and two admitted to wanting to but feeling as if that were not an option. Half of the participants specifically reported trauma, multiple of whom have needed counselling as a result. Over half of the women reported experiencing physical harm and decline of their illnesses as a direct result of the actions of medical practitioners. There were countless instances of negligence reported and 17 out of 20 participants had their experiences or concerns dismissed by medical practitioners. Four reported being yelled at by doctors, others reported being mocked and laughed at, and Julia, 55, stated "If my daughter had not been in the appointment with me, I still maintain to this day that I would have walked into traffic and ended it all right then and there. [That appointment] was one of the most demeaning and humiliating experiences of my life." She was not the only participant to mention such an experience. Lack of respect, inhumane treatment, and emotional, verbal, and mental abuse were common complaints. Over half of the participants had been made to feel crazy or had psychiatric diagnoses suggested for their physical symptoms. A significant majority of the participants found that the rareness and invisibility of their illness had a large (negative) impact on their experiences with the medical system leading up to and during diagnosis. One participant encapsulated some of these patterns in this statement: "[medical practitioners] look at any young woman who believes she has a rare disorder as an attention seeking hypochondriac who hopped on [G]oogle one day and decided she wanted to play sick" (Eve, 22)

**Conclusions:** The experiences of these twenty women are not unique. Attention needs to be paid to this topic as individuals are suffering at the hands of our medical system every day while so many Canadians live in ignorance of this problem. The system of training and educating medical practitioners needs to change – practitioners should be required to study critical disabilities studies and to keep up to date with new research (such as changing diagnostic criteria). Patient-provider communication desperately needs to be improved, and training programs, additional curriculum, and increased accountability measures can aid in this endeavour. Most of all, practitioners must understand that patients are the experts on their own experiences, and practitioners should not lead with mistrust. The most common wish of the women interviewed was to be listened to and treated with respect. This should be the foundation of our healthcare system, and yet it remains out of reach for so many. A person should not be considered lucky to be treated like a human being by a medical professional.