TITLE PAPER

**ABSTRACT**

**CCS Concepts**

**• Information systems~Multimedia information systems   • Computing methodologies~Virtual reality • Information systems~Multimedia information systems   • Human-centered computing~Graphical user interfaces • Applied computing~Life and medical sciences.**

**General Terms**

Design, Experimentation, Performance.

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**Keywords**

Virtual Rehabilitation; Rare Diseases; Physical Therapy; Numbness; Tingling; Range-of-motion; Grip strength.

# INTRODUCTION

Definition of Rare Diseases (one paragraph)

Las instituciones públicas y privadas de la salud han expresado como objetivo principal "asegurar condiciones en las que las personas puedan estar sanas", generando soluciones si aparecen problemas de salud inesperados o persistentes o factores ambientales que pongan en riesgo a grandes poblaciones.

Las instituciones de salud trabajan con profesionales de diferentes áreas, para investigar las causas que ponen en riesgo la vida y salud de las poblaciones para luego prevenir, mitigar o suprimir los inconvenientes generados. Sin embargo, esta actuación no sucede con las enfermedades conocidas como raras o huérfanas, que afectan a pocos sujetos y están dispersos en el mundo con una variedad de trastornos y síntomas debido a variaciones genéticas o a la etapa de aparición en el sujeto(Chaves, 2017; Lippe, Diesen, & Feragen, 2017) (Kole & Faurisson, 2009; MedigenePress, 2017).

Las enfermedades raras se definen como tales, dependiendo de la prevalencia en cada país. La Unión Europea considera una enfermedad rara si 1:2.000 sujetos tienen esa enfermedad (Eurordis, 2014); en Noruega 1:10.000 sujetos tienen esta enfermedad (Helsenorge, 2016); en Taiwán 1:10.000 sujetos (mediográfico, 2015); en Italia 1:20.000 sujetos (mediográfico, 2015); en Estados Unidos 1:5. 000 sujetos (Cortés, 2015; Centro de Información Genética y Enfermedades Raras, 2017a); en Japón 1:2.500 sujetos (Cortés, 2015); aparentemente los pacientes son pocos, dispersos por todo el mundo y distribuidos en las 5.000 a 8.000 enfermedades raras registradas (Alonso, Hawrylak y Gómez, 2010; Boycott et al..., 2013; Institute of Medicine National Academies of Sciences, 2010).

El 80% de las enfermedades raras son de origen genético y la diferencia se debe a infecciones bacterianas o virales, factores ambientales o alergias (Alonso, Hawrylak y Gómez, 2010; Boycott et al., 2013; Institute of Medicine National Academies of Sciences, 2010).

Los pacientes con enfermedades raras, además de enfrentarse a los síntomas de su patología, deben experimentar: 1) la falta de conocimiento y experiencia de los expertos clínicos; 2) las limitaciones de acceso a los sistemas de salud; 3) la baja disponibilidad de medicamentos (Antiñolo & Lozano, 2010); estos inconvenientes han provocado retrasos en el diagnóstico, tratamientos inadecuados o experimentales e incluso tratamientos dañinos (Budych, Helms & Schultz, 2012).

Las enfermedades raras son a menudo enfermedades que amenazan la vida, o las condiciones físicas o mentales del sujeto (Cohen & Biesecker, 2010) como la enfermedad de Huntington, la espina bífida, el síndrome de X frágil, el síndrome de Guillain-Barré, la enfermedad de Crohn, la fibrosis quística, la distrofia muscular de Duchenne, el sidrome de Werter y la esclerosis lateral amiotrófica (Alonso et al., 2010; Chaves Restrepo, 2011) (2017). Las enfermedades Raras más frecuentes en los infantes son osteogénesis u osteogénesis imperfecta, fenilcetonuria, albinismo oculocutáneo, acondroplasia.

Algunas enfermedades raras son compatibles con una buena calidad de vida si se diagnostican a tiempo y se tratan de forma óptima (Boycott, Vanstone, Bulman y MacKenzie, 2013).

Prevalence and incidence of rare diseases (one paragraph)

Common of rare diseases in childhood (different paragraphs)

Main cause of rare diseases (genetic and non-genetic)

Main drawbacks at the present time related to rare diseases: 1) lack of information; 2) low availability of drugs; 3) high social cost; 4) poor profitability; 5) patient’s uncertainty; 6) experimental treatments

A rare disease can affect the subjects in their mental, behavioral and sensory abilities

Definition of epileptic encephalopathy (one paragraph)

Types of epileptic encephalopathy

Symptomatology of epileptic encephalopathy

Traditional rehabilitation techniques of epileptic encephalopathy.

Physical rehabilitation (one paragraph)

Sensory rehabilitation (one paragraph)

Cognitive rehabilitation (one paragraph)

# RELATED WORK

Examples of Virtual Rehabilitation in patients with neurological disorders.

Examples of Virtual Rehabilitation in childhood with disorders (children with Cerebral Palsy, children with Autistic spectrum disorders, etc)

The are no studies of technological systems based on virtual Rehabilitation for children with epileptic encephalopathy…

# METHODS

## The Participants

## The System

Our technological system is comprised of

## VR exercises

# PROCEDURE

Before the first session, the therapist tested all the participants

Figure 2. Participant using the system.

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# RESULTS

# DISCUSSION AND CONCLUSIONS

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