DEAFENING SILENCE ON FRIEDREICH'S ATAXIA IN LEBANON:

HEALTH BELIEF MODEL APPROACH

A Thesis

presented

to

the Faculty of Humanities

at Notre Dame University-
Louaize

In Partial
Fulfillment

of the Requirements for the
Degree

Master of Arts in media
studies/advertising

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by
MARIANNE HAKIM
SPRING 2018

Notre Dame University - Louaize
Faculty of Humanities

Department of media studies

We hereby approve the
thesis of

Marianne
Hakim

Candidate for the degree of Master of arts in media
studies- advertising

ndu CHAIRPERSON MEDIA STUDIES

Dr. Maria Abou Zeid Chair

Christy

Dr. Christy Mady Thesis Advisor

Jessica El-Khoury

Dr. Jessica El Khoury Committee Member

Dr. Kamal Al Kassir Committee Member

Acknowledgments

I am blessed and grateful for my advisor and two readers as I considered them my support group and trust circle every step of the way. I am first and foremost thankful to my thesis advisor, Dr. Christy Mady for her guidance, support and encouragement in tackling this delicate research. I am also grateful to my first reader Dr. Jessica El Khoury who was of a great help in choosing and perfecting my theoretical framework. Last but not least, my gratitude extends to my second reader, Dr. Kamal L Kassir for believing in me and sharing his knowledge and expertise with me.

Finally, I would like to thank Mrs. Hyam Fakhoury who facilitated the data access of the patients, my friends and the volunteer students who helped me carry out these interviews. Every contribution led me to take this thesis to another level. Emphasizing and comprehending the difficulties of people living with Friedreich Ataxia drove me to establish a non-profit organization for FA in Lebanon. So I thank each for the support hoping to make a difference in forgotten people's lives.

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Abstract

This research aims to gain understanding of the health behaviour of individuals affected with a genetic disease, Friedreich Ataxia in Lebanon and comprehend the consequences of the lack of awareness and circulation of information about FA on those individuals in comparison with international communication efforts through the Health Belief Model theory.

The research method used throughout this thesis is qualitative and interviews with sixteen Lebanese participants afflicted with FA aged between 11 to 49 years old were conducted relying on an interview guide that tested seven constructs of the HBM. The results eventually answered the research questions.

This study concludes with limitations that were faced by the researcher, as well as the research being a contribution to knowledge and an opening to further research on FA among Lebanese patients.

Chapter I: Introduction

1.1 My Friedreich's Ataxia

When diagnosed with Friedreich Ataxia fourteen years ago at the age of seventeen, I distinctly remember a strange feeling of relief and acceptance. When I began developing symptoms, I clearly knew that something is wrong with me, however it took doctors four years to set the diagnosis. So defining it helped validate what was happening to my body and putting a name on it was weirdly relieving. Being diagnosed also gave me a sense of purpose. However, as my symptoms progressed, my adrenaline slowed at some point and I felt discouraged that I still had to fight this disease alone despite having a great support group of friends and family. I realized how unfamiliar this disease is to doctors, therapists and society in Lebanon and that realization brought about feelings of anger, hopelessness, and bitterness. I had recourse to worldwide research and international medical advices on what to do and how to cope. For the first three to four years, the balance and gait difficulties were still manageable, yet tiring. At university, I didn't need assistance yet, however it was hard for me to walk for long distances and go up and down the stairs. It wasn't until seven years from the diagnosis that I started to use a crunch to maintain my balance and human assistance to walk; I started to experience excessive fatigue, coordination and control of the upper body and speech difficulties.

With time and experience I learned that wallowing in that sad place wouldn't accomplish anything, it was then that the positive determinism hit me. So I began physical therapy, work out programs, hydrotherapy, speech therapy and psychotherapy to help improve my daily routines; I consult a neurologist and do follow up exams on a regular basis. Even though I know physical therapy and exercising won’t stop my progression, however it controls the regression of the symptoms, strengthens my muscles and train my body and mind to cope in a way that helps me function and have a good quality of life despite all physical and psycho-social challenges. Then I realized there must be a whole community of people like me struggling with this orphan disease in Lebanon that I don’t know of, just like FA communities abroad. I felt this urge to research and learn more about the lack of communication and knowledge about FA, thus find these people in order to understand their struggles and maybe lay a hand in the future to embrace this life together despite all obstacles.

1.2 Understanding Friedreich’s Ataxia

So what is Friedreich’s Ataxia and what can it do to the body, the mind and the lifestyle people with FA? Schulz and Pandolfo (2013) define Friedreich's Ataxia (FA) as a recessive genetic neurodegenerative disease caused by the loss of function of a mitochondrial protein, frataxin (FXN). It was identified in 1863 by Professor Nikolaus Friedreich. Friedreich's Ataxia is an autosomal recessive inherited disease, often occurring in childhood, from7 to 11 years or adolescence from 12 to 18 years, but sometimes in adulthood from 18 to 25 years of age (Al Kassir, 2016). The disease is manifested by disorders of the gait, control of movement, speech difficulties, lack of balance and coordination of the upper limbs, along with muscle weaknesses associated with other neurological signs, as well as cardiomyopathy and sometimes diabetes. Yet FA disease does not affect intellectual abilities. The disease progresses gradually and can lead to immobility, walking becomes impossible without assistance after 10 to 20 years of evolution, coordination and control of the movements can get heavier and the speech blurrier. Every symptom varied from one person to another as well as the severity degree. The average life expectancy is very variable from an average of 37.7 years + - 14.4 years, because of cardiac and respiratory complications.

To improve the autonomy and capacities of the patient suffering from FA, the patient requires continuous monitoring and regular check-ups with the physiotherapist, the psychologist, the speech therapist, the cardiologist and the attending physician for a better orientation and stable health and optimization of the functional performance (Marquer A. et al, 2014).

There is, currently, no pharmacological intervention to cure or delay the progression of FA although multiple promising pharmacological trials are in progress and new therapies to restore mitochondrial function and genetic therapy are being appraised. In the meantime, functional rehabilitation plays an important role in the treatment of this orphan disease in order to improve the quality of life and functional independence of individuals living with FA (Maring and Earllaine , 2007; M, 2013). Physical rehabilitation has been one of only a few methods shown to be of benefit to people with

FA, particularly in the management of the negative effects of the disease on mobility and function (Delatycki, 2009).

Physical therapy aims to prolong motor function, or the ability to walk, and achieve a better quality of life as long as possible while minimizing pain, deformity, immobility and disability (Naqvi, 2017). More often than not, the disease is described as the drunken disease. Parents belonging to the United States’ Friedreich’s Ataxia Research Association (FARA) mention that one of the recurring incidents is being approached by a stranger who would question whether their kids were drunk since it is impossible for an FA kid to walk in a straight line. Eventually the FA patient resorts to the use of a wheelchair (Friedreich's Ataxia Fact Sheet, 2014). A rehabilitation intervention exists even when a patient becomes wheelchair dependent in order to maintain and strengthen his capacities to transfer from one position to another, stand from the seat with adequate positioning using support and sit back safely in the wheelchair. This is called “step transfer” and could be used as a focus of therapy (Milne, Campagna, Delatycki, & Corben, 2013). Prevention exists as well. It is even recommended to consult a geneticist doctor for an accurate risk assessment because it is technically possible to perform a prenatal genetic test in the brothers and sisters at risk of a patient, or search for the genetic abnormality if it exists in a new couple with a history of ataxia in their families (Nadege C. et al, 2009).

1.3 Rare Disease, Rare Communication

> "Although rare, Friedreich's ataxia is the most common form of hereditary ataxia, affecting about 1 in every 50,000 people in the United States" (NIH National Institute of Neurological Disorders and Stroke, 2010).

In Lebanon, according to Fakhoury (2016), program manager of Access & Rights of Disabled People, 243 people in Lebanon, both male and female are registered as having FA in the Ministry of Social Affairs. Having a disability card allows them to benefit from the ministry's facilities; for instance the person affected with FA is infallible from custom fees, gets technical aids for only 30% of their price from certain non-governmental organizations and can benefit from free medical consultations and physical therapy sessions offered by their center. These individuals can take advantage as well of free entrances to public places and discounts on any Middle East airline ticket for them and the one accompanying them.

> Yet, one of the main issues in tackling the disease remains the lack of information, especially in Lebanon. Informational websites, online medical journals, social media, research centres and organizations in the US, Europe and Australia exceed by far the very few articles that mention FA in Lebanon. The homepage of goFAR European fund organization states that:

> “Without establishing a worldwide cooperation, we will never be able to put an end to the disease and save future generations from this progressive disabling pathology.” (RUBI committee, 2005)

The lack of scientific knowledge and quality information on the disease often results in a delay in diagnosis. The lack of education will lead to poor health prevention of the regression of the symptoms, thereby leading to a bad quality of life.

> “Functional rehabilitation plays an important role in the treatment of this orphan disease (Joyce R Maring et al, 2007) by improving quality of life and functional independence.” (Sarah C et al, 2012)

Although enormous progress is being made every day, unfortunately in Lebanon, the medical research development is not monitored and the quality of life that people with FA are leading is poor. In his doctoral dissertation on Friedreich’s Ataxia, Dr. Kamal Al Kassir stated that:

> The interdisciplinary work must be more elaborated and well discussed between the physiotherapist, the psychologist, the speech therapist and the attending physician for a better decision especially since the patient and his family lack information about the neurological, functional, cardiological and diabetic problems. (Al Kassir, 2016)

Al Kassir points out to the evident lack of awareness of the disease within the different factions of the Lebanese community. There is a serious lack of knowledge by the specialized doctors, unfamiliarity with the FA pathology and therefore a weakness in helping and guiding patients affected with FA. Add to that, the nonexistence of psychological or civil society support groups, the lack of supporting literature (in English and Arabic) and media campaigns on the disease leave the patients feeling alone and deserted as they find no means to become integrated within the bigger community. The lack of awareness is standing in the way of progress, both in terms of giving patients living with the disease a better life and providing them with the necessary information and facilities to navigate a healthier and more productive existence.

My experience with FA attests to all of the above. The path that I have been treading since I discovered I had FA 14 years ago has been quite difficult due to the lack of orientation and poor flow of medical information. I always have to refer to research done abroad to identify and understand what is happening with me. I go through different online material posted about FA on social networks, online medical journals, blogs, FA associations and websites. Hardly any Lebanese doctor or physician is familiar with the disease or ongoing treatments; it was hard having to educate the professionals in the field. Besides the lack of professional medical help the overall infrastructure in Lebanon made it hard for me to move around and most places are not easily accessible.

There's incredible on-going research to find a cure for FA since researchers were able to depict the cause of the rare disease's disorder (FARA's mission and organization, 2017). Therefore the on-going implementation of a better comprehensive medical approach to FA will lead to progress in the treatment of the disease and important gains will be made with the increased cooperation between clinical and scientific research as well as the sharing of that knowledge with people affected or involved with FA. In the Friedreich Atxia Research Alliance website, a section for the most recent FA research publications, scientific news, as well as information on upcoming conferences and symposiums exists as guidelines. These advances will lead to the development of new diagnostic and therapeutic procedures (Larkindale, 2018)

A better understanding of the health behaviour of patients and consequences of the silence on FA in Lebanon will be the first step towards making a difference in the medical field and in the patients' lives. It is the evident gap between the circulation of information in Lebanon and abroad that drove me to conduct this study hoping for a better quality of life for all of those whose voices are being muted.

1.4 Objectives of the Study

Having shown that Lebanon suffers from a lack of academic studies and awareness campaigns on FA, this study examines, through the use of the Health Belief Model

(HBM), the status, knowledge and coping mechanisms of Lebanese patients with FA. The study will be conducted using the, a qualitative method to investigate, the main HBM proposed concepts of perceived susceptibility, severity threats, benefits and barriers of FA among Lebanese patients. The aim is to identify how and if these variables prompt patients to take action and build self-confidence to get the needed help whether through communication networks or facilities.

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The study also seeks to explore the consequences that result from the absence or minimal presence of communication about FA in Lebanon. The ultimate purpose is to be able to assess and understand the patient’s mental and physical statuses in order to find optimal ways to spread awareness to educate FA patients and their surroundings, orient and support them to lower the regression of the disease by acquainting them with options for a better quality of life.

1.5 Structure of the Thesis

The thesis will be structured as follows:

1.5.1 Chapter I: Introduction to the Thesis

This chapter explains the personal motives behind this research study and a detailed description of Friedreich Ataxia. It highlights the lack of communication about FA in Lebanon and consequently states the objectives of the study.

1.5.2 Chapter II: Literature Review

This chapter starts by establishing a literature comparative analysis between the little FA information diffused locally and the abundant international flow of data and communication efforts. Then, this chapter reviews five studies of different health issues relying on the Health Belief Model to understand health behaviour of people from different countries since none of the studies have explored Friedreich Ataxia.

1.5.3 Chapter III: Theoretical Framework

This chapter explains the Health Belief theory, its components, and its objectives and explores examples of its use and application. The HBM is used to comprehend the consequences of lack of communication and awareness about FA in Lebanon and to understand health behaviour of Lebanese afflicted with FA though the HBM constructs that consist of perceived susceptibility, perceived severity, perceived barriers, perceived benefits, cues to action, self-efficacy and modifying factors.

1.5.4 Chapter IV: Methodology

This chapter discusses the qualitative methodology of this study and a justification of using this method and the research design chosen. It points out the advantages of conducting semi-structured interviews using a guide. In addition it describes how each set of questions of the interview guide tests one construct of the HBM and each construct represents a theme conceptualized in this paper. Furthermore, the sampling participants are introduced and the data collection and analysis are reviewed.

1.5.5 Chapter V: Findings and Discussion

This chapter examines the findings of the qualitative interviews conducted based on the thematic constructs of the HBM and relate them to the literature and to the research questions.

Chapter II:

Literature Review

Although an extensive amount of literature is available on health beliefs about different diseases abroad, none has explored Friedreich Ataxia yet in Lebanon. Therefore, in an attempt to understand behaviours of individuals living with FA, factors and the consequences of the silence on the rare disease and how it is affecting the patients’ quality of life, the literature review will first provide an overview of the information available on FA in Lebanon. It will examine the use of the health belief model on different diseases abroad to examine how they were designed to promote health education, intervention and prevention to promote healthier lifestyles. Moreover, a comparison between the circulation of medical advances and communication is established between Lebanon and other countries to highlight the prevalence of information diffusion and the effects of the lack of awareness and education about FA.

2.1 Information about Friedreich Ataxia in Lebanon

As previously mentioned, there are 243 people in Lebanon who suffer from Friedreich's Ataxia. These are the people registered with the Ministry of Social Affairs, whose data information was retrieved on the 25th of February 2017.

Their demographics are as follows::

- Gender: male: 53.72% and Female: 46.28%
- Age: 61.98% belong to the bracket age of 35-63, 25.21% are aged between 18 and 34, 8.68% are aged above 64 and 4.13% range between 6 and 17.
- Location: 50.83% are located in Mount Lebanon and the other 50 are evenly distributed amongst other districts.
- Health condition: 68.18% of people's health condition is good, 26.03% is average and only 5.79 is bad.
- 51% of the people use wheelchairs: 88 persons benefited from a regular wheelchair, and 40 requested one that should be wheeled by others; and 20.66% use walking aids (crutches, canes,,,)
- Education level: 13.64% never went to school, 69.83% attended high school but did not graduate, only 2.89% have a high school certificate; 5.795 attended college but dropped out and 6.61% graduated.

- Employment: 10.33% of the people work; 40% of them work in the private sector, 56% work as freelance and 4% are undefined.

Despite the fact that there is a good number of FA patients in Lebanon, information on the disease and how to deal with it is mostly unavailable. Moreover, the circulation of information among the medical staff as well as the patients is extremely low and slow, hence creating a severe knowledge gap between the medical advances and patients’ knowledge.

FA’s awareness in Lebanon is very low. Barely any medical studies, research or support groups currently exist. In his doctoral dissertation on FA, Al Kassir (2016) stated that there is no association in Lebanon that supports Friedreich Ataxia. This triggered him to carry out his study, which would serve as a guide or reference to the FA medical and patient community especially that all the data presented in his project is a summary of evidence-based practice, European and American Guidelines.

There is no significant academic and medical research on Fredrich's Ataxia in Lebanon. While browsing the Internet, only a few medical reports and articles that are out-dated appeared. Yet even these articles do not tackle the actual disease, its treatments and medical advances. One of these articles, entitled "Keratosis and Friedreich's Ataxia: In the Same Sibship", dates back to 1948. It was found in the *Journal of Heredity* in the American University of Beirut. The article explored a new ancestry in certain members of an Arab family, in which Keratosis, one of the most common noncancerous skin growths in older adults, may have led to FA happened (Haddad & Pipken, 1948).

Another article was published in Pubmed, US National Library of Medicine and in the *Journal of Medical Research* in 1995, whereby a Lebanese doctor in the American University Hospital in Beirut reported a case of a female presented with FA at the age of 91which is thought to be the only such case, to be reported at this age, in the literature (Abyad & Kligman, 1995). However it does not address the problem nor does it indicate any medical development or discuss the ongoing research either.

The most recent and valuable source, as mentioned before, remains a dissertation written by Dr Kamal Al Kassir. Al Kassir tackled for the first time the importance of physical therapy in Friedreich's Ataxia in his doctoral studies in physiotherapy entitled "Prise en Charge Physiotherapique de L'Ataxie de Friedreich » (Al Kassir, 2016).His findings are based on a case study of a 28 year old male affected with Friedreich Ataxia. He established his balance sheets and evaluation, his treatment plan whether physical rehabilitation or drugs, precaution and assessed his situation according to the International Classification of Functioning, Disability and Health (ICF). Al Kassir referred to two articles as well by Letts, Wilkins,, Law, Stewart, Bosch, & Westmorland (1998), whose findings highlight the importance of physical therapy and the progress of patients thanks to rehabilitation.

2.2 International FA Communication Efforts

Research on rare diseases, FA in particular, has been expanding and so have the means of communicating these advances to the people in many countries in Europe (S, V, C, M, S, Y and MA, 2015), Australia (A, DJR, ML-H, DR, 2014), USA (Wood, 2016) and Canada (Ataxie Canada, 2017). This availability of information makes the data on FA easily accessible

> Communicating, informing and sharing take many forms. It is done through blogs, social media, articles, books, informational websites, medical journals, press releases and most importantly research associations and non-governmental organizations.

Certain FA associations and support groups provide forums where members can share their views and discuss their hopes and aspirations, share their experiences and identify with others who have been going through the same condition; these groups also organize regular meetings, social gatherings and events.

Below are only a few examples of associations and different communication tools for awareness and research in the USA, Canada, Australia and Europe.

In the US, FARA, Friedreich Ataxia Research Alliance, is one of the most significant of all associations for medical research and fundraising. Its mission is to assemble and focus the resources and relationships needed to cure FA by raising funds for research, promoting public awareness, and aligning scientists, patients, clinicians, government agencies, pharmaceutical companies and other organizations dedicated to curing FA and related diseases. “FARA Mission/ Organization”

NAF, National Ataxia foundation is an example of an association with social forums.

NAF, National Ataxia foundation’s mission is dedicated to improving the lives of persons affected by ataxia through support, education, and research. The Foundation's primary purpose is to support promising ataxia research and to provide vital research programs to find a cure. Moreover it provides the latest news and information through different media and it helps connecting the ataxia community through conferences, events, meetings and chat rooms. “About National Ataxia Foundation” Dave Lewis wrote a book narrating his experience in living with FA. He spent the last three years of his life writing his memoir to provide information and inspiration to countless others. Proceeds from the book purchased through NAF will be used to support promising Friedreich's ataxia research. (Lewis, 2010)

CAFA Canadian Association Familial Ataxias, Claude St-Jean Foundation is an association whereby the president’s grandchild and some of the board members are afflicted with FA and each one of them has a biography to convey hope and perseverance; a number of social activities are organized to spread awareness and raise funds such as “the walk to fight FA”. On another note, Roger Foley who is president of CAFA’s central branch is donating his time, talents and efforts to help CAFA in social activities and supporting aw well other organizations struggling with disabilities despite battling daily Ataxia. (Sommerfield, 2012)

BabelFAmily is a worldwide group of volunteers whose objective is to support FA community of patients, doctors, researchers, scientists and associations in their mission to find treatments and a cure for Friedreich’s ataxia and to facilitate the exchange of information and news in 10 languages and spread awareness. The NGO is headquartered in Spain but offers contacts, newsletters and social channels and supports FA-related efforts worldwide to members of the FA community (BabelFAmily, 2002).

NINDS, National Institute of Neurological Disorder and Stroke is a part of the U.S. National Institutes of Health that conducts and funds research on brain and nervous system disorders. NINDS has an informational website that includes Friedreich’s Ataxia information page where information about the disorder and research are communicated. Its mission is to reduce the burden of neurological disease. (NINDS Friedreich's ataxia information page, 2013)

Help FA in SA, Help Friedreich Ataxia in South Australia is a blog created for people interested in Friedreich Ataxia in South Australia. It provides a relaxing place to share and communicate what is going on, as well as links to FA groups and information from around the world. FAinSA is a non medical site for patients, families and friends of FA. All comments are a purely personal nature and do not replace advice from trained medical professionals (Hosking, 2007)

Other supporting materials include the PatientPlus articles written by UK doctors and are based on research evidence, UK and European Guidelines. They are designed for health professionals to use (Wright & Hartee, 2010)

> Another example is Stephanie's Hope- A cure for FA, which is a Facebook page of an organization that exists to raise awareness about Friedreich's Ataxia and funds for the Friedreich's Ataxia Research Alliance.

Support groups are also essential. A good example is the French Facebook group, "Ataxie de Friedreich." The group was created and is managed by patients, for patients. It targets Francophones of various nationalities. It is a place of exchange for families, friends, caregivers, affected from near or far by an ataxia (including Friedreich’s), and it offers a confidential space of sharing. This group provides support for everyone, breaking isolation and advancing knowledge about the disease; as well as concrete advice on disability and its repercussions in everyday life (Ataxie de Friedreich, 2011).

2.3 Use of the Health Belief Model for Different Health Issues

The Health Belief Model is a combination of health education and specific interventions that are designed to promote change to healthy lifestyles. This thesis explores the use of the HBM model to shed a light on the factors and effects of the silence on FA and the poor quality of life it engenders. It first shows how HBM was used to promote better and more fulfilling lifestyle for different health issues.

2.3.1 Application of the HBM in HIV Prevention in Cameroon

“The HBM was identified as the most commonly used theory in health education, health promotion and disease prevention“(Tarkang & Zotor, 2015).Tarkang and Zotor (2015) used the Health Belief Model (HBM) to investigate the factors associated with consistent condom use to prevent Human Immunodeficiency Virus/ Acquired Immune Deficiency Syndrome (HIV/AIDS) among senior secondary female learners in Mbonge subdivision of rural Cameroon. The essential idea of the HBM in this study is directed towards promoting health, knowledge about HIV and mode of its transmission and preventing it by showing ways to avoid it such as use of condoms, therefore anticipation in teenagers’ behavioral change. Padden, Ramsey and Bibbs estimate that the HBM affects people’s behavior when they realize the harmful health effects and understand that these adverse effects can be avoided or minimized. (Padden, Ramsey and Bibbs, 2008). In other terms, the HBM assumes that a person will avoid HIV if he’s aware of its seriousness and that he has options to avoid it, whether it’s abstinence from sex or use of condoms. Second, the HBM supposes that if teenagers perceive the value and benefit of using condoms to avoid HIV, then they would use them. Third, The HBM presumes that a person will take action if he has self-efficacy or confidence that he can do it. According to Dennill, King, Lock and Swanepoel,(1999) (qtd inTarkang & Zotor, 2015), the HBM for the HIV prevention study asserts that people’s motivation to take action is based on three components.

The first is the students’ perceptions about HIV, which is made of six constructs:

- Perceived susceptibility to HIV/AIDS, in other words how strongly they believe to be susceptible of getting the disease.
- Perceived severity of HIV/AIDS or the level of seriousness of the disease and its effects in their perception
- Perceived benefit of condom use, meaning the perception of the value of the health intervention
- Perceived barriers to condom use and health behavioral change
- Cues to action for condom use and education or peer support

- Condom use self-efficacy

The second component constitutes the modifying factors such as socio-psychological, attitudes, beliefs, and personality traits. (Groenewold, Brujin and B|ilsborrow, 2006) Structural and demographic variables such as race, age, culture, knowledge, influence as well the individuals’ behaviours.

The third component comprises of the benefits of taking preventive measures. The HBM is thus an appropriate theory to be used in HIV/AIDS prevention and public health research; it is applicable to sexual education programs if used for primary prevention programs that aim to avoid a negative health condition such as HIV, Sexually Transmitted Diseases (STDs) or pregnancy by increasing contraceptive methods. And it is valid as well for secondary prevention programs, which objectives are to increase early detection of sexual diseases, provide early treatments and minimize the spread of unprotected intercourse.

2.3.2 Health Belief Model and Adolescents' Fertility Control

Since the Health Belief Model is based on motivating people to take action, it has been applied to many health education subjects including sex education. This study is a follow-up to a sexuality education program conducted originally by Eisen, Zellman and McAlister (1992) using the Health Belief Model and the Social Learning Theory (SLT) written in the online journal Resource Center for Adolescent Pregnancy Prevention (2007) . The study was done on rural to urban low-income youth and recruited 1444 participants in their eighth- and ninth-grade classes from California and Texas and one Northern Californian school district to compare their regular curricula with the HBM-SLT intervention. Participants were individually interviewed with a questionnaire before the onset of the program, which objective was to encourage them to practice safe sex and prevent incidence of teenage pregnancy. SLT speculates that individuals learn from one another through observation, limitation and modeling, which includes attention, memory and motivation.

In addition to assessing modifying factors such as beliefs, knowledge and attitudes and behaviors related to sexuality, the current study combines four theoretical constructs of the Health Belief Model and Social Learning Theory in order to:

- Increase teenager’s awareness of the probability of pregnancy- Perceived susceptibility
- Emphasize the negative consequences of teen pregnancy- Perceived severity
- Highlight the benefits of delaying sexual activity or using protection- Perceived benefits of sexual avoidance
- Understand perceived barriers of abstinence and contraceptive use

As a result of this study, authors assumed that the HBM-SLT intervention would lead to fewer transitions to sexual activity and an increase in consistent contraceptive use; as the program's objectives were to increase knowledge of and motivation for abstinence or contraceptive use, measure the change in sexual and contraceptive behavior and compare the impact of the HBM-SLT with other programs (Eisen, Zellman & Mcalister, 1992). In the case of promoting abstinence, it was found that applying the HBM is not a good fit in terms of taking action. The avoidance of a perceived threat of a negative health result is not always the main reason why teenagers abstain from sex; it could be for religious principles or simply for logistic reasons (Eisen, Zellman and McAlister, 1992).

There was a lack of change in females' behaviors, possibly because they already have a high level of awareness regarding the risks of pregnancy especially those who were virgins initially; the impact of the HBM-SLT program was not as great as for experimented males. Their consistent use of contraception and their awareness and avoidance of pregnancy risks maximized.

2.3.3 Application of the HBM on Osteoporosis

Tuener, Hunt, DiBrezzo and Jones (2000) in the "Design and Implementation of an Osteoporosis Prevention Program Using the Health Belief Model" explored probable perceptions of seriousness, susceptibility, benefits and barriers and possible cues to action and variables to understand why some women do not take action to prevent osteoporosis.

McBean, Forgac and Finn (1994) (qtd in Tuener, Hunt, DiBrezzo and Jones, 2000) affirmed that osteoporosis is considered to be a serious public health problem that affects 25 million people in the US, 80% of whom are women. Results showed that cues to action and self efficacy in addition to modifying factors affected women’s perception of susceptibility, seriousness, benefits and barriers and therefore their behaviour; Modifying variables consisted of age, personality, knowledge, ethnicity, socio-economic, media, health professionals, incentives, personal relationships and others (Stretcher and Rosentock (1997) (qtd in Tuener, Hunt, DiBrezzo and Jones, 2000).

As a result of the study, the Osteoporosis Prevention Program (OPP) was designed and implemented using the HBM. OPP addressed several of the components in order to tackle major reasons for non-compliance concerning recommendations for the prevention. In summary the OPP was a success as perceived severity, perceived susceptibility, benefits, self-efficacy and cues to action got increased while perceived barriers were decreased, which encouraged participation such as free of charge participation fees and flexible timings.

The program provided informational and instrumental support including nutrition and exercising classes for a period of one month. The participants were provided with hand-outs, illustration and information from the `national Osteoporosis Foundation and American College of Sports Medicine.

2.3.4 Application of the HBM for Dengue Fever

World Health Organization, (2000) (qtd in Lennon, 2005) stated that dengue fever is a severe health threat worldwide caused by any one of four types of dengue viruses spread by mosquitoes; these larval mosquito breeding sites include many human-made trash items such as cans and tires and can be reduced by human behavior.

Dengue is considered to be an influenza-like infection that affects all age groups. However it can induce death in developing countries like Pakistan because of improper water systems and sanitation, inadequate infrastructure, occurring natural disasters etc. (Z, FZ, A ,T et al., 2015)

Dengue prevention is the most effective way to reduce the risk factor of and control getting infected. Therefore the study by Siddiqui ,Ghazal, Bibi, Ahmed,and Sajjad (2016) evaluated public awareness and health beliefs concerning dengue fever in order to develop control and preventive strategies of the disease. Since the awareness and knowledge levels are found to be low in Karachi, The authors suggested that information should be diffused using the HBM constructs in order for people to take preventive and control measures.

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VL &SS (2008) (qtd in Siddiqui ,Ghazal, Bibi, Ahmed,and Sajjad , 2016) showed that adequate knowledge about dengue leads to preventive actions and modifying variables. It revealed, for instance that health beliefs are a significant factor of knowledge and prevention in Pakistan. The flow of information about Dengue should increase people’s self-efficacy so that they would actually be ready to adopt preventive practices. The perceived barriers that would stop people from taking action should be controlled and the benefits should be highlighted

> “With reference to the HBM, framing health messages for dengue prevention according to HBM constructs could result in an effective dengue control program in Karachi”. (JF, 2005)(qtd in Siddiqui ,Ghazal, Bibi, Ahmed,and Sajjad , 2016)

However, the HBM has some limitations as it does not account for environmental factors that might prevent an individual from adopting preventive measures even if knowledge and awareness about dengue and self- efficacy were increased and perceived barriers got decreased such as poor infrastructure, bad sanitation and water supply. Moreover, the cues to action cannot be assessed precisely by the HBM, since it is hard for people to recall what triggered the behavioral change.

2.3.5 Use of the HBM to Reduce Obesity

A study done by Romano, Scott and Smith (2014) sought integrate the Health Belief Model through one-on-one health coaching sessions to reduce obesity amongst African American and Hispanic populations living in the Unites States, promote heath education and change to healthy lifestyles and assist specialists in explaining and predicting health behaviors within these individuals.

The participants were comprised of 209 faith-based males and females from 15 churches, who participated in a 16-week program, Village Heart BEAT Building Education and Accountability Together, which integrated the HBM through one-on-one Health Coaching (HC) sessions. This program offered the participants free courses and classes of weight management, group exercises classes, water fitness, healthy living seminars, health coaching, monthly team challenges and more (Romano, Scott & Smith, 2014).

The researcher quoting Burke (2009) agreed that change required a reason that outweighed the trouble associated with giving up on an old habit. They also agreed with Madsen (2003) who emphasized the importance of having an incentive that would prompt participants to change their habits. These are known as perceived benefits and self-efficacy in the Health Belief Model. The HBM promotes healthy behaviours by focusing on the individual's motivation and likelihood to prompt behavioural change, individuals' personal perceptions and modifying factors.

Romano, Scott & Smith (2014) suggested that adopting healthy lifestyle within African Americans and Hispanics can be hard as they strongly belong to a culture of unhealthy habits and their healthy weight perception can be distorted. However, they concluded that when combined with the Health Belief Model through Health Coaching, the Village Heart BEAT program was successful in terms of progressive decrease of participants' eating routines and body fat, thus increase of their weight loss, when compared to those who did not participate in Health Coaching. (Romano, Scott & Smith, 2014)

Chapter 3: Theoretical Framework

This chapter deals with the Health Belief Model, which forms the theoretical framework of the study. It first starts by....

3.1 Understanding the Health Belief Model

The Health Belief Model (HBM) is a psychological model that attempts to explain and predict health behaviors. It is by far the most commonly used theory in health education and health promotion (Glanz, Rimer, & Lewis, 2002; National Cancer Institute [NCI], 2003). It is considered as one of the first theories developed to understand the change in relation to individuals’ health behavior and to create health educational material and messages.

The HBM was first developed in the 1950s by social psychologists Hochbaum, Rosenstock and Kegels working in the U.S. Public Health Service to explain the failure of a free tuberculosis health-screening program (Hochbaum, 1958). Since then, the HBM has been adapted to explore a variety of long- and short-term health behaviors, health promotion and education and different risk behaviors including sexual risk behaviors and the transmission of HIV/AIDS (Rosenstock, 1974). It is stated that health behavior is determined by personal beliefs or perceptions about a disease influenced by intrapersonal factors and the strategies available to decrease its manifestation (Hochbaum, 1958).

The Health Belief Model was identified as the most commonly used theory in health education, health promotion and disease prevention and therefore it is used as a framework for this study in order to understand FA patients’ behavior, their perception of and personal beliefs about the disease and the consequent lack of communication and silence about it in Lebanon. When used properly, it provides structured assessment of the patients’ data in terms of capacities and motivation to adopt a healthier behavioral change (Stanhope and Lancaster, 2000). Through the HBM, this research would be of great benefit to comprehend the reasons behind the silence on FA, the effects of lack of information & communication about it on people concerned and the absence of taking healthier measures. The HBM can be a good fit to create health education program in the long run that focuses on primary prevention to prevent the rapid regression of Friedreich Ataxia and promote physical reeducation; on another hand, HBM can be used for secondary prevention to increase early detection of the disease so early treatments can be ensured and other options for newlywed couples to explore (Resource Center for Adolescent Pregnancy-Prevention, n.d). The motivation of people affected with FA to adopt physical and psychological rehabilitation measures in order to prevent the rapid regression of the disease are based on several constructs. First of all how susceptible they think they are to contract Friedreich Ataxia. An already existing case in the family will increase the risk of inheriting it or if one of the parents has FA, the possibility of transmitting it to the kids would be of a higher possibility. Second, their perception of how severe the consequences that FA engenders, would dictate their behavior. Third, their belief of the value and benefit of knowledge, psychological and physical rehabilitation plays an important role. Same goes for whether they believe that effectiveness of the treatment is worth the cost. In other terms, adopting a rehabilitation lifestyle knowing the disease is degenerative requires incentives that are worth the discomfort and pain. Fifth patients’ motivation is based as well on barriers’ identification of what is stopping them from taking and maintaining action. And last would be everything and everyone that could influence one’s perception and might trigger them to change their behavior.

3.2Thematic constructs of the Health Belief Model

The Health Belief Model affirms that individuals’ motivation to take action in terms of preventing or learning about a health issue is based on different components that would contribute in understanding and explaining their health behavior. Perceived susceptibility, perceived severity, perceived benefits and perceived barriers serve as the main constructs of the model. However, the model has been expanded to include cues to action to activate people’s readiness to take action, self-efficacy as the most recent addition to the model taken from the work of Bandura and modifying variables that influence as well their health behavior.

3.2.1 Perceived Susceptibility

The first component of the HBM is based on how strongly a person believes he is susceptible to contract the health condition in question. Perceived susceptibility defines an individual’s perception of vulnerability to this particular health issue (Resource center for Adolescent pregnancy prevention, 2007).

Perceived susceptibility motivates people to take action. For instance, people use sunscreen to prevent skin cancer and high-perceived risk is what prompts people to adopt healthier behaviors.

Only when the perceived susceptibility to contracting HIV infection and other sexually transmitted diseases is high and associated with practice of unsafe sex, that men who have sex with other men will be prompted to be vaccinated against Hepatitis B (de Wit et al., 2005) and to use condoms in an effort to decrease HIV infection (Belcher et al., 2005) and transmission of other sexual diseases.

Since FA is genetic, prevention in the world and particularly in Lebanon begins with the education of individuals at risk and their parents and families.

In Lebanon, two genetic research centres (Hôtel Dieu de France and American University of Beirut) are available for early detection of FA; the diagnosis is confirmed by the study of the DNA taken by a blood test.

It is recommended to consult a geneticist for a precise assessment of the risks because it is technically possible to carry out a prenatal genetic test among the brothers or sisters at risk of a patient, or to look for the genetic anomaly if it exists in a new couple having a history of ataxia in their families. (Nadege C. et al, 2009).

3.2.2 Perceived Severity

This concept is based on diffusion of medical information and knowledge; however it also refers to one’s beliefs in the serious effects and consequences if contracted with the health condition (Mc Cormicl-Brown, 1999). Even if individuals recognize they are susceptible to get a health issue, they would not take preventive or avoidance measures until they realize the seriousness of the negative social and physical implications of it on their lives; only then that they will get motivated to take action. For example, the flu is known to be a minor illness that only requires resting for a couple of days before recovery. However if someone originally has asthma, then contracting the flu could lead to severe consequences. In that case, the perceived severity of the flu would change, which would influence the individual’s preventive or avoidance behaviour (Theories and approaches: Health Belief Model, 2005).

Another example would be of HIV/AIDS; people would adopt preventive methods such as condom use because they perceive it as a serious infection with a severe multitude of consequences.

3.2.3 Perceived Benefits

The construct of perceived benefit is based on a person’s belief of the value and effectiveness of a health intervention to reduce a risk or negative impact. It refers to a belief in the expected outcomes of adopting a new healthier behaviour to avoid a risk occurrence. It’s like when people stop smoking because they actually believe that it is better for their health. Moreover, the HBM proposes that the belief about the effectiveness of condom use in preventing HIV/AIDS should correlate positively with their consistent use (Hiltabiddle, 1996). Perceived benefits play an important role in promoting breast cancer screenings to prevent breast cancer. The earlier breast cancer is found, the greater the chance of survival. Therefore when women believed that breast self exams are beneficial, they did them more frequently as an effective mean of early detection (Graham, 2002).

3.2.4 Perceived Barriers

Perceived barriers refer to one’s belief in the tangible and psychological costs and one’s personal evaluation of the obstacles that limit a person to carry out a new health- related behaviour (Groene, Bruijn and Bilsborrow, 2006). And in order to overcome these personal barriers and to adopt new health-related measures, an individual needs to believe that the benefits of the new behaviour outweigh the consequences of sticking to the old health behaviour (Centres for Disease Control and Prevention, 2004). Besides psychological costs, several concrete barriers to health action could affect people's decision to take particular actions or engage in preventive measures such as their accessibility factors, costs, duration and complexity of the action itself. However, it is only when an individual realizes that he or she has the capacity and motivation to deal with these barriers, that he or she would be able to take the necessary actions (Polit and Hungler, 1999). Whenever the barriers are identified, the objective would be to reduce them through reassurance, incentives and assistance. The following are two examples of sexual health education; in the condom use education example, the youth's personal barriers to condom use are that the condoms limit the feeling or they are too embarrassed to talk to their partner about it. The educational program highlights ways to eliminate or reduce these barriers; for instance, teach the youth to put lubricant inside the condom to increase sensation for the male and have them practice condom communication skills to decrease their embarrassment level. Another example is the one of Sexually transmitted diseases screening or HIV testing. Youth have difficulties to go the clinic or to be seen at the clinic by someone they know. And once these barriers are identified, the aim is to explore ways to eliminate or reduce these barriers as well such as brainstorming transportation and disguising options.

3.2.5 Cues to action

People's behaviour is also influenced by cues to action. This is another component of the Health Belief Model be it events, people or things that would activate readiness. It can be applied by providing how-to information and promoting awareness and reminders (Glanz et al, 2002).

The HBM’s cues to action are events or experiences such as media reports (Graham, 2002) or mass media campaigns. Personal and interpersonal include illness of a family member, advice from others, influence by another person who may have been susceptible to the same health condition, reminder postcards from a health care provider (Ali, 2002) or health warning labels on a product such as “smoking kills” on a pack of cigarettes. All of these cues to action play a prevailing role in motivating individuals to comply with the recommended action after having dealt with reduced barriers (Polit, and Hungler, 1999). This construct refers to the occurrences and practices that fuel one’s need to carry out behavioural changes as follows:

> **“**Knowing a fellow church member with prostate cancer is a significant cue to action for African American men to attend prostate cancer education programs (Weinrich et al., 1998).”

> **“**Hearing TV or radio news stories about food borne illness and reading the safe handling instructions on packages of raw meat and poultry are cues to action associated with safer food- handling behaviours (Hanson &Benedict, 2002).

3.2.6 Self Efficacy

In 1988, self-efficacy was added to the original four beliefs of the HBM for a better adaptation to the challenges of changing consistent unhealthy behavior (Rosentock, Strecher, & Becker, 1997). Self- efficacy refers to one’s confidence in the ability to perform an action that would motivate the individual to adopt and sustain an act (Bandura, 1977). One would try something new or different in case one thinks he or she is capable of taking the action correctly and responding well to new obstacles and difficulties.

Expectations of self-efficacy and beliefs would influence one’s behaviour and determine his or her coping behaviour, amount of efforts and level of endurance in the face of challenges and hostile experiences (Bandura, 1977).

Perceived self-efficacy is one of the key predictors of STD and HIV sexual risk reduction. Consequently, it refers to confidence in one’s ability to execute and carry out new sexual preventive measures like successfully using condoms. On another note, referring back to the osteoporosis example from the literature review, perceived self-efficacy and perceived barriers are the strongest determinants of one’s preventive behavior (Turner, Hunt, DiBrezzo and Jones, n.d). “Women who do not engage in the recommended level of weight bearing exercise tend to have low exercise self-efficacy, meaning they do not believe they can exercise, and perceive there to be significant barriers to exercise” (Wallace, 2012). These women do not exercise as a consequence.

3.2.7 Modifying Factors of HBM

It is true that perceived elements in addition to cues to action of the HBM influence one's health and related behaviour. However, modifying factors play a crucial role in altering one's perception, therefore affecting one's educational and preventive health behaviour (Onega,2000);(Cormarck, 1999) (qtd in Tarkang and Zotor, 2015).

Modifying factors include main variables that in turn are comprised of numerous characteristics that influence awareness:

- Demographic and socio-demographic variables: age, gender, race, culture & traditions, nationality, education, literacy
- Psychological and psychosocial variables: socio-economical status, household income, attitudes & beliefs, personality traits, peer pressure, past experiences
- Structural variables: knowledge and motivation

Educational status is an example of a socio-demographic variable that could affect a person's perceptions of susceptibility to and the severity of suffering unpleasant effects resulting from HIV/AIDS infection (Cormarck, 1999); another psychosocial variable that can be used as structural variable can affect a teenager's decision of using contraceptive methods during sexual activity (Onega,2000). Past experiences can have a major effect on one's perceptions; for instance, having been diagnosed with and treated from basal cell skin cancer, will definitely increase that person’s perceived susceptibility; however it can diminish one’s perceived severity since it was easily treated and cured. (Jones & Bartlett Learning, 2010)

3.3 Application of HBM constructs on Friedreich Ataxia

Through the HBM, this thesis explores the perceived susceptibility, severity threats, severed benefits and severed barriers of Friedreich Ataxia among Lebanese patients and how modifying factors, cues to action and self-efficacy affect patients’ behaviour to seek help and get a better quality of life. Based on the literature review, the data obtained highlights the gaps between the knowledge about FA, thus the absence of practices to enhance patients’ quality of life and the education and promotion programs of other diseases abroad and the abundance of data diffusion about FA outside Lebanon.

3.3.1 Perceived susceptibility refers to one’s perceived vulnerability of contracting

FA. An already existing case in the family will increase the risk of inheriting it or if one of the parents has FA, the possibility of transmitting it to the kids would be of a higher possibility.

3.3.2 Perceived severity of FA means one’s beliefs about how serious FA is. Carrying out active and healthier behavior would occur if the severity level of its progressive consequences on a person’s life is significant enough to try to manage it the soonest. Their perception of how severe the consequences that FA engenders would dictate their behavior

In other words, one will change his or her behaviour if aware of the aggravation of joint deformities and postural complications, the lack of coordination and control of the upper limbs, the weakness of the core and lower limbs muscles, the speech difficulties and heart potential problems. This construct is immensely influenced by knowledge and awareness about FA.

3.3.3 Perceived benefits refers to one's belief in the efficacy of adopting re-education measures and having regular follow-ups by doctors and physicians to reduce the regression and seriousness of FA’s symptoms. One’s belief of the value and benefit of knowledge, psychological and physical rehabilitation plays an important role. Same goes for whether they believe that effectiveness of the treatment is worth the cost. In other terms, adopting a rehabilitation lifestyle knowing the disease is degenerative requires incentives that are worth the discomfort and pain.

As mentioned earlier, there is currently no treatment that can stop the course of the disease; Al Kassir states that the drugs used fight the symptoms or complications of the disease and especially cardiomyopathy. For this reason, the treatment remains purely indicative under the control of the doctors and makes extensive use of the coherent functional re-education carried out by the physiotherapist to limit as much as possible the functional losses and to prevent certain complications; regular follow up is necessary to control and adjust the medical and functional treatment as well as the ergonomic adaptation of the patient with his environment (Al Kassir, 2016). Morton and Bastian (2009) are quoted when they found through their re-education work proven by statistical work, that physiotherapy is very effective for ataxic people in terms of balance, coordination and ambulation (Morton and Bastian, 2009).

In a study conducted by White, Leib, Farmer and Biesecker (2010), transitional life events in individuals with Friedreich ataxia was investigated. Researchers found that patients need not only physical care from their providers, but also emotional and psychosocial support.

3.3.4 Perceived barriers are associated with one's psychological and perceptible costs of getting proper treatments and medical check-ups. Patients' motivation is based as well on barriers' identification of what is stopping them from taking and maintaining action. Individuals living with FA would engage in therapeutic measurements only if they believe that these new practices would benefit them while outweighing the costs and having the capacity and motivation. For example, first step towards scheduling a session with a physical therapist is identifying one's personal barriers; one can think the session is too tiring, time-consuming and costly or simply he or she is not motivated to try and commit. Fear of falling has been identified as one of the major barriers to move forward among FA patients. Brook V et al concluded that the traumatic consequences of falls increase with the number of falls. The fear of falling must also be sought and prevention of falling is therefore essential.

However if the individual is well educated and aware of the benefits of therapy, given assistance

and support throughout the session and provided with an opportunity to integrate in the workplace, their interest level to overcome these barriers will increase.

3.3.5 Cues to action are influenced by personal experience, media, information, people or events that would activate and trigger willingness to change health behaviour. For instance, if the clinic environment of the physical therapy session is well adapted like existence of ramps and grab bars, and staff is well alerted and helpful and the factors that may aggravate the risk of falling are carefully managed such as slippery floors, one might be pushed to try a session as the fear of falling will be diminished. Media play an important role in spreading awareness about FA and highlighting the benefits of adopting medical and therapeutic measurements. Moreover, support needs to be maximized through continuous education that is framed by physicians, physiotherapists, cardiologists, psychologists, and speech therapists (Joyce M. et al. , 2103), facilitating social and professional integration.

One's relationships or life jobs would definitely motivate patients to get proper treatments.

3.3.6 Self- efficacy implies that expectations of self-confidence would influence one’s

behaviour and determine his or her coping mechanisms and continuous efforts facing FA’s consequences. A study by White, Leib, Farmer and Biesecker (2010), captures transitional life events altered by Friedreich ataxia and the impact of these events on an affected individual's life course. Researchers confirm that FA increased the complexity and extent of transitional events, which commonly represented significant loss and presented challenges to self-esteem and identity among study participants. Therefore chronic and degenerative illness highly affects self-efficacy so unless patients believe they are capable of trying a new exercise correctly, have the guts and are ready to face the challenges and difficulties ahead of them, they wouldn’t try to carry out new therapeutic practices.

3.3.7 Modifying factors influence people’s perceptions about and awareness of Friedreich Ataxia, thus alter their health behaviour. They factors include demographic and socio-demographic variables, psychological and psychosocial variables and structural variables. For example, Lebanese mentality concerning disability affects immensely the perceptions of people affected with FA, therefore could limit their trials to integrate in the social and professional fields. Plus, one’s self-efficacy to try a new workout exercise let’s say, would be affected. Another socio-economic factor might affect the new health behaviour. For instance, the household income must be sufficient enough for an individual to be able to afford medical treatments or consultations. Add to that one major variable, which is knowledge that might diminish perceived susceptibility, perceived severity of FA and perceived benefits of getting treated; and increase perceived barriers to carry out new therapeutic measures. Knowledge and beliefs influence directly education and behaviour of people affected with FA.

Chapter 4: Research Methodology

This chapter will discuss the methodological orientation of this study by identifying the research method and the research approach to participants and the chosen sample. The chapter will also identify the research questions and the concepts to be analyzed. The chapter ends with an evaluation of the validity and reliability.

4.1 Research Design

The study will rely on the qualitative research methodology to investigate the consequences of the silence on Friedreich’s Ataxia in Lebanon and to provide a rich and detailed understanding of the health behavior, emotions and perceptions of those affected with FA through the health belief model. The basis of the research lies in the interpretive approach to social reality.

Madrigal and McClain (2012) state that “Qualitative research studies can providedetails about human behavior, emotion, and personality characteristics that quantitative studies cannot match.” While quantitative research requires data collection control to statistically compare results, qualitative research allows a deeper and more flexible data analysis encouraging participants to expand their responses and express their opinions and feelings better (Madrigal and McClain, 2012). Particularly in this research, it establishes a psychological and emotional understanding of patients’ experiences and perceptions on the different constructs of the HBM in Lebanon. In an article entitled Data Analysis in Qualitative Research: A Brief Guide to Using Nvivo, Wong (2008) quoted authors Mays N and Pope C when they wrote about the advantages of qualitative research in health care issues and how qualitative methods explore the people’s experiences, their perception and behavioral attitudes within social structures.

4.4 Research Questions

The research questions are based on the literature review which showed the discrepancy between the availability of information about FA in countries like the US, France and Canada and its lack of availability in Lebanon besides shedding light on how the HBM applies to people with different health conditions. To acquire a better comprehensive understanding of the health behavior of the patients suffering from Friedreich’s Ataxia and the consequences of the lack of information about it in Lebanon using the HBM constructs, this thesis addresses the following research questions

RQ1: What construct of the Health Belief Model is mostly slowing down the willingness of taking action towards FA?

This research question aims to evaluate the obstacles standing in the way of individuals affected with FA and preventing them from taking preventive action to slow down the regression of the disease.

RQ2: How HBM constructs such as perceived susceptibility, severity, benefits and barriers and cues to action impact self-efficacy to take action? (and vice versa)

This research question seeks to make sense of concerned people's perspectives, knowledge and perceptions to test how these factors prompt them to adopt new and preventive measures and vice versa.

RQ3: To what extent do modifying variables play a role in behavioral change?

This research question attempts to arrive at a more in-depth understanding of the impact that psychological, socio-demographic, socio-economic, culture and knowledge factors impact one's behavioral change.

RQ4: Based on all constructs of the HBM, to what extent is the model applicable in Lebanon?

Although the Health Belief Model is often used to promote health education and prevention, this question explores the HBM's ability to alter the behavior of people living with FA in Lebanon.

4.5 Conceptualization

The research questions are based on the constructs of the Health Belief Model, elaborated in the theoretical framework and applied to different diseases in the literature review. This part tests each concept of the Health Belief model among Lebanese people diagnosed with FA. The data analysis will be done under themes and each theme is a concept of the HBM. The aim is to comprehend people’s health behavior and the effect of FA’s lack of communication on them.

4.3.1 Perceived Susceptibility

This refers to one’s opinion of risks of contracting FA mainly based on the probability of a genetic anomaly in the family. One can assume to have the disease it if there is family member or someone he/she knows of who is experiencing the same symptoms. Sometimes the doctor can predict the diagnosis before getting DNA tested or even the individual concerned could do their own research if a family member is diagnosed with FA or if they are experiencing unfamiliar symptoms.

4.3.2 Perceived Severity

This means one’s estimation and awareness of FA diagnosis and its repercussion on one’s life. In other terms, it refers to one’s belief of the severity of FA symptoms, its consequences and the risks of staying passive and not taking corrective action.

4.3.3 Perceived Benefits

This theme represents one’s belief in the advantages of getting supplements and medications, being followed up by their doctor and physician, keeping up to date with medical advances and regularly exercising and doing physical therapy in order to slow down the progression of the disease, monitor the cardiac symptoms, thus have a better quality of life. Testing the patient and the doctor’s belief in the efficacy of the advised action are crucial. A doctor or therapist should believe in reducing and monitoring the neurological symptoms through rehabilitation and meds so he would advise it to patients.

4.3.4 Perceived barriers:

Through this theme, personal barriers to know and learn about FA and get treated are identified. In other words, adopting rehabilitation action depends on one’s belief in the concrete and psychological costs and if the perceived benefits outweigh the costs. For instance, if one lacks motivation and thinks that he is not capable of doing physical therapy because he gets tired and it’s not worth it, then he won’t even try.

4.3.5 Cues to Action

This represents any strategy that activates readiness among people affected with FA to become active, get regular checkups, ask for medical and technical aids to improve their quality of life, do physical therapy to help slow down the regression of the disease. This concept is every experience, media news, event or person that would promote awareness about FA and trigger one to adopt behavioural change of lifestyle.

4.3.6 Self-Efficacy

This refers to FA patients' confidence in their ability to exercise regularly and do physical therapy, integrate in the job market, express themselves and communicate with others. People, who are confident that they deserve to be given an opportunity to pursue their education and to be integrated in the workplace, are the ones who will work on making it happen.

4.3.7 Modifying Factors

These factors consist of the psychological, socio-economic and socio demographic variables that would affect one's decision making, perception and behavior.

4.4. Data Collection

4.4.1 Semi-Structured Interviews

This study's findings are derived from the research questions, which in turn are tested through semi-structured interviews either face to face or through the phone. An interview guide is formed for the interviewer that consists of the different themes to be tested with their relating questions in a certain order. The semi-structured interviews allow for the development good understanding of the environment and sometimes stray from the course of the questions when appropriate. Interviews also allow for the observation of the interviewees, their environment, behaviour and attitude. Cohen and Crabtree (2006) affirmed in their Qualitative Research Guidelines Project:

> The inclusion of open-ended questions and training of interviewers to follow relevant topics that may stray from the interview guide does, however, still provide the opportunity for identifying new ways of seeing and understanding the topic at hand.

Semi- structured interviews was selected as a research method for this study to understand health behaviour of people living with FA, and explore the consequences of the absence of communication, education and awareness about FA in Lebanon. The categorization of the interview questions is thematic and based on the concepts of the Health Belief Model elaborated in the theoretical framework. I believe the design selected for research is the most suited to achieve answers to the proposed research questions; body language and non-verbal communication are as crucial as verbal responses especially that such a delicate and personal subject will be discussed. It will be focused on the interviewees’ thoughts, perceptions and knowledge and experience regarding FA. Semi- structured interviews are known to provide reliable and comparative data and give the interviewees freedom to express their feelings and thoughts (Cohen and Crabtree, 2006).

A paper-based interview guide will be followed and jot notes will be taken when possible to capture the interviewees’ responses. However, that could be distracting from developing a dialogue between the interviewer and interviewee; therefore tape-recording is crucial if the respondent doesn't mind. Each interview will then be transcribed for analysis

4.4.2 Sampling: Research Participants

To get information on people who suffer from FA in Lebanon, I contacted Hyam Fakhoury, program manager of access & rights of the Ministry of Social Affairs'office. She advised me to send a request for information, by email, to Judge Abdallah Ahmad, general manager of the ministry of social affairs. Four months later, I got the approval to access information. Upon meeting with Ms. Fakhoury, she informed me that there are 242 people suffering from FA in Lebanon; you can find attached appendix 1. However, only 100 agreed to be interviewed in case of research when they first registered for their disability card.

Ms. Fakhoury gave me contact details to 15 male and 15 female participants from different age groups, regions, education levels and health and work statuses. The contact was made through her despite the fact that it was time consuming and she was staying after her working hours for a couple of days to help me. Parental consent was given over the phone to interview their kids with FA in their presence no matter how old they are. Two sisters insisted the interview takes place at their workplace because their parents tend to be bossy and controlling. Only 15 were responsive (10 females and 5 males); two refused to participate and didn't specify why and 13 were unreachable. The 16th participant called me herself as she found out from another patient that I was conducting this research and wanted to get in touch with me to schedule a phone interview.

Two of the participants, who are sisters, live in Anta Akhi, a non-governmental organization that takes into account adults with disabilities, accompanies them throughout their life and offers them a place to live and be taken care of on all aspects. They have severe speech difficulties and their neurological symptoms are very advanced; they are incapable of moving a finger alone. Moreover, they seemed a bit disconnected. They were in Sesobel, Anta Akhi's sister association that takes care of children with disabilities, when they were younger, and the management team has been witnessing their regression year after year.

Anta akhi provides them with trainings in terms of awareness about FA and formations to better accept themselves and find meaning to their lives despite their disease. Therefore the interviews were scheduled with their caregiver and the general manager. The regions from which the interviewees came are: Zouk Mosbeh, Tripoli, Zagharta, Beit Chabeb, Beit Meri, Ballouneh, Kahhale, Haret Hreik, Burj El Barajne, Adloun and Choueifat.

Only 3 of the interviewees still walk and 4 of them work - Kamal has gym equipment and supplements shop of his own, Assaad works in an advertising company and 2 sisters Joy and Nancy work in Arcenciel association

8 of the interviewees are under 30 years old; 4 are in their thirties and 4 are above 40. 2 are university graduates and 1 is in his 1st year and another dropped out; 2 have technical

diplomas and the rest dropped out of school in elementary or secondary classes or technical schools.

A sheet for the basic information of the interviewees is attached (appendix 2); their names in the sheet are fake to preserve confidentiality and privacy.

4.4.3 Approaching Participants

After Ms. Hyam Fakhoury called the participants and asked for their interview approval, I personally conducted eleven interviews and I have contacted the AUB center for civic engagement and community service and three students volunteered and carried out five interviews due to the difficult accessibility of the participants' buildings and hard to reach areas. Carine and Joe are medical students and Marla is a public affairs student. These specific interviewees live in the fourth and fifth floors without elevators and hardly any parking spaces. However I had previously met with the students and briefed them about FA and the study's objectives; and thanks to the interview guide and questions I prepared, they were able to gather comprehensive and reliable responses using a tape recorder and jotted notes. According to Bernard (1988) (qtd in Cohen and Crabtree, 2006):

> Semi-structured interviewing is best used when you won't get more than one chance to interview someone and when you will be sending several interviewers out into the field to collect data.

Participants were reassured they are being interviewed for an academic purpose and that their identity would remain anonymous.

4.4.6 Data Analysis

Qualitative Data Analysis consists of moving from data collection into forms of interpretations and behavior understanding of the people and environments investigated. This process involves writing and identification of themes (Lewins, Taylor and Gibbs, 2010)

For this study,. I will use the deductive approach relying on the predetermined framework that of Health Belief Model and deriving from the research questions to analyze the interview transcripts. Representation of audible and visual data into a written form as an interpretive process is the first step in analyzing the data. I think it will be challenging because . Two “yes” can differ. Trying to interpret the verbalized data can be tricky since I’ll be trying as much as possible to take into consideration the attitude, the tone of voice and the interaction of the interviewees and their families. Interview transcripts and observations collected will be explored, interpreted and divided into themes in order to make sense of the outcomes through an analytical descriptive narrative form. The data analysis will be presented thematically and will be discussed in their relation to the concepts proposed by the Health Belief Model or any other concepts that may emerge during the course of the interviews. Each set of questions will test one of the concepts of the HBM classified as themes of the study: perceived susceptibility, perceived severity, perceived barriers, perceived barriers, self-efficacy, cues to action and modifying variables. The findings of the elements that dictate health behavior of individuals affected with FA in Lebanon will be related to the literature where different health conditions were investigated through the HBM and the international diffusion of information and communication about FA are noticeable. The data analysis and findings will be compared and contrasted with the existing literature.

4.4.7 Validity and Reliability

In his conference paper entitled Validity and Reliability in Qualitative Research, Brink (1993) stated that "validity and reliability are key aspects of all research." Le Comple and Goetz (1982) mention that the validity of the study refers to the findings and research methods' validity, accuracy and truthfulness (qtd in Brink, 1993). Reliability of a research consists of consistency of the information, results and methods, stability and reliability of the investigator to use different measurements while being able to collect information accurately (Selltiz, Wrightsman and Cook, 1976- qtd in Brink, 1993).

One of the key factors affecting validity and reliability is error, therefore the researcher must attempt to lower the margins of error and increase the validity and reliability of the responses, first by making sure that the interviewees are aware of the nature of the research, second by backing up the research method used with different methods of data collection, third by keeping an audit track in addition to the interviews, transcription and field notes, fourth by allowing participants to approve on the truthfulness of the data collected and fifth by having a second outside researcher double checking and questioning the methods and the accuracy of the data collected (Brink, 1993 ; Maykut and Morehouse, 1994).

Therefore, this research paper is presumed to be valid and reliable since participants received a phone call explaining the reasons behind the interview Moreover, during the interviews, the interviewers reconfirmed the nature of the research basic data information of the interviewees were retrieved from the Ministry of Social Affairs and already existing literature of the Health Belief Model and comparison analysis of FA communication. Plus, the interviews were audio taped in addition to transcriptions and the interviewees double checked with the participants whether their notes are valid. Lastly, an advisor is continuously following up the study and suggesting change and more accurate methods.

Chapter V: Findings and Analysis

This chapter will analyse and interpret the results of the participants’ responses. It will also relate the analysis of their answers to the concepts of the Health Belief Model in the theoretical framework chapter and tie them back to the findings in the literature review chapter. This chapter will be divided into seven sections, each accounting for one theme and every set of interview questions resulting from each theme. The themes correspond to the HBM constructs: perceived susceptibility, perceived severity, perceived barriers, perceived benefits, cues to action, self-efficacy and modifying factors. The analysis and interpretation of the responses will eventually answer the research questions of the study.

5.1 Perceived Susceptibility

The first theme that was tested was the first construct of the Health Belief Model. The questions that helped identify perceived susceptibility were:

1- At what age did the symptoms start?
2- What kind of symptoms did you first experience?
3- Do any of your family members experience this condition?
4- Did you know that you could be susceptible to FA?
5- What kind of doctor did you consult with and why?
6- What is your doctor's diagnosis?
7- Before getting tested for FA, did you have an idea what it was? If yes, how?

When asked if they knew whether they could be susceptible to FA, five out of the sixteen did not even know what they are diagnosed with to answer this question. Although Samar and Nayla, Dareen and Lama, as well as Nancy and Joy are three sets of sisters, they couldn't tell since their symptoms started respectively at the age of 11, 10 and 16. Only Omar's mother was able to detect FA and asked herself to run the adequate tests at a very early age, since she had relatives who were suffering from FA and she is married to her cousin. All the fifteen other respondents had not heard of FA before.

Samar (37) and Nayla’s (42) health conditions are very bad; they have severe respiratory problems and are unable to communicate verbally. Instead, they mime, therefore the actual communication was with the psychologist and general manager of Anta akhi association since the sisters live there. Serge (27), Mayssa (20), Zeina (11), Souraya(33), Saber (17) and Nadine (34) don’t recall the steps their parents took for them or the doctors they went to when first diagnosed with FA. The remaining eight participants remember their paediatrician or family doctor who referred them to a neurologist. To sum up, only one participant out of sixteen believed he was susceptible to get FA thanks to his mother’s knowledge and experience.

Based on the findings of the communication about FA in Lebanon in the literature review, it can be assumed that the low perceived susceptibility of individuals afflicted with FA –and their families results from the poor flow of information and lack of awareness about FA in Lebanon. Despite its high importance, this component with regards to patients’ knowledge may not be essential since whether one knows he or she is susceptible to contracting FA cannot stop it from happening. Its importance springs forth when an individual affected with FA wants to have a baby, then a DNA test would confirm if FA would be transmitted or not so the parents would make an informed decision.

The results show that that perceived susceptibility is directly influenced by knowledge but does not stand in the way of adopting preventive measures.

Some of the literature’s findings affirm this assumption and others do not.
A study carried out by Romano, Scott and Smith (2014) did not account perceived susceptibility to be a prevalent construct of reducing obesity.
However, as a result of an adolescent fertility control research done by Eisen, Zellman and McAlister (1992), it has been assumed that the HBM-SLT intervention would lead to an increase of contraceptive use rather than abstinence through increasing teenager’s perceived susceptibility of the probability of pregnancy.

5.2 Perceived Severity

The second theme to be tested is the second construct of the HBM and is associated with the following interview questions:

1- What are you diagnosed with? What are the symptoms that cause you discomfort?
2- Are they evolving? Any idea how to slow down the regression?
3- Do you follow up exams every now and then?
4- Did you have an interest in learning more about your condition? If yes, what sources did you consult with (doctors, family, friends…)
5- At what age were you diagnosed?

6- What kind of assistance do you need? (technical, human)

Mayssa, Zeina, Saber, Souraya and Nadine didn’t know what they are diagnosed with when asked; their parents showed us the medical exams and reports. Mrs. Roula Najm, director of Anta Akhi association informed us that Samar and Nayla, just like every other patient, were given awareness sessions about FA. She said: every patient here has the right to be educated on his disease, so we make sure he/she receives the right information, however we work most on bringing out their value whether they are productive or not and most importantly highlight their role throughout their life”. Dareen and Lama, Rachel, Joy and Kamal were interested to know about FA and do internet research and seek international information; Sami is very knowledgeable and was a part of an ataxia association in Belgium and Nancy showed interest when she started to work at Arcenciel. However Serge, Saber and Nadine are not interested to know more about FA and are content with the doctor’s diagnosis and mayssa and zeina’s parents (since zeina is eleven) don’t know who to refer to besides the doctor.

The main neurological symptoms amongst every participant in addition to excessive fatigue are balance, control, coordination and speech difficulties. Serge (27), Saber (17), Sami (40), Kamal (30) and Zeina (11) having cardiomyopathy, get regular medical follow-ups and a yearly heart echo. Sami, Saber, Zeina, Samar (42) and Nayla (37) have diabetes and do blood tests every now and then consequently. Each of the sixteen patients dealt with the regression of the disease differently; Sami was in denial for a very long time and gained a lot of weight until he realized that he can’t fight the severe consequences of FA and has to live with it and treat its symptoms. Thanks to the Belgium association he is subscribed to, he is very aware of the seriousness of FA. Kamal is very knowledgeable as well and leads a healthy lifestyle. Nancy did not want o know anything about it especially when the symptoms were still manageable until she started to work in arcenciel; however she is not up to date on new researches and does not consult a doctor.

Samar and Nayla are in a very strong regression phase and due to the difficulty of communication, I could not know whether they were aware of FA's seriousness. Mayssa knew FA is regressive, however she did not know she will develop cardiomyopathy and diabetes but she does not do exams. Serge and Joy have been depressed since their diagnosis up until today. They do not want to know anything about FA nor do they want to get check-ups and physical therapy sessions. Saber was not aware of the seriousness of the consequences and still doesn't but does not feel daily regression but yearly regression. Even if he feels sometimes energetic, he is afraid of falling down so he does not move.

Souraya is not very familiar with FA consequences and doesn't have the patience to change anything. Zeina was unresponsive and started to cry in the middle of the interview and went to her room. Her mother makes sure she visits the doctor from time to time and states that the symptoms are evolving slowly and exercising from year to year helps. Dareen and Lama's regressions are very fast; they researched FA when first diagnosed and they are convinced that there is nothing to be done. Nadine does not follow up on FA and doesn't know a lot about it more than what her doctor told her.

Omar is very knowledgeable and up to date and is getting proper help thanks to his mother's support.

To sum up only five of the participants including Nancy, Rachel, Omar, Kamal and Sami are aware of the seriousness of FA and are following up on the news and updates of the disease. The lack of diffusion of information about FA and the low awareness level in Lebanon already discussed in the literature review, made it hard for the eleven remaining participants to know about FA and only relied on doctors' explanation when diagnosed. This is very limiting. The non- existence of support groups and associations made most of the patients fearful and unprepared to face the consequences of the disease. Most of them live in denial and ignorance rather than face up to the disease and fight its regression. The blatant lack of support from groups, the government and the medical body has left these patients alone to fend for them against a disease they barely know about.

The literature shows that the increased awareness of the perceived severity of the disease prompts patients to take preventative measures and invites them to take immediate action. In the study of HIV Prevention in Cameroon conducted by Tarkang and Zotor (2015), it is estimated that people's behaviour is affected when they realize the harmful effects and seriousness of the consequences of HIV and that these unpleasant effects can be avoided or minimized.

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Hunt, DiBrezzo and Jones(2000) affirmed that the osteoporosis Prevention Program (OPP) was a success as perceived severity and all other components got increase while perceived barriers decreased. The results showed that the new constructs added to the initial model affected the four perceived components.

Moreover, It the Dengue prevention research in Karachi, Siddiqui ,Ghazal, Bibi, Ahmed,and Sajjad (2016) showed that little of information about Dengue is circulated in Pakistan. Therefore once knowledge increases, perceived severity will too, preventive behaviours will be adopted consequently.

In a study done by Romano, Scott and Smith (2014) to reduce obesity amongst African American and Hispanic populations living in the Unites States, the authors concluded that participants would be influenced by the increased of perceived benefits rather than the perceived threats.

In conclusion, increasing perceived severity alone of any health issue and FA in particular would not affect people's behaviour but it's a step towards knowing and defining the difficulties in order to solve them, adapt and live with them the best way possible. It also acts as a stimulus for people to take action. All the studies in the literature confirm that once the patients knew of the perceived severity of the disease or illness, they took action. This study of FA in Lebanon shows that people's inability and/or refusal to gain knowledge on the disease has stood in the way of them facing it and of them dealing with its consequences.

5.3 Perceived Benefits

This theme is the third construct of the HBM and is tested through these questions:

1- Do you follow up medical research and news about FA?
   If yes, how?
2- Are you on medication and are there measurements you take for treatment?
   If yes, specify
3- How and where do you get treated and if you don't why not?
4- Who is your doctor/does he follow up with you/ what is his advice?
5- Do you think that you will get a long term benefit from the preventive measurements you are taking?

Ten out of the sixteen respondents do not follow up medical research and news about FA; the remaining six get their information from the internet and new through FA websites and three out of these six (Kamal, Omar, and Rachel) belong to American and French support groups for FA on facebook where life experiences and the latest advances are shared.

Dareen and Lama, Rachel, Joy and Nancy, Nadine and Sami were advised by their doctors not to do physical therapy and that it is pointless since the disease is regressive. Rachel, Nancy and Sami did not trust their doctor's advice and relied on international associations and on their gut feeling. Sami works out at home after the physical therapy centre advised him to stop, Rachel and Nancy do physical therapy sessions when they can. Joy used to do hydrotherapy and physiotherapy but stopped because she found it tiring and gave up. Serge, although he knows he was better when he was doing physical therapy, he stopped because he feels it’s pointless. Serge, Mayssa, Saber and Souraya don’t have a doctor for monetary reasons and they don’t see the value of being medically followed up. Therapists do stretching for Samar and Nayla in their rooms and get regular checkups from Anta Akhi’s doctors. When visiting Dareen and Lama, they asked me twice if I seriously have FA too so when I told them I do but exercise and physical therapy is a must, they were completely shocked and Claudia said: “how come no one told us that? How can you do it? Are you sure you have FA?.” Zeina,Omar, and Kamal are the only ones having a physician follow their case and get treated. Sami and Rachel exercise at home although recommended otherwise.

Eight including Nancy, Mayssa , Zeina, Rachel, Saber, Omar, Kamal and Sami believe they will get moderate benefit from the preventive measurements, however three participants (Mayssa, Rachel and Saber) are not doing physical therapy for different reasons. Based on the interviewees’ responses, seven participants were not given adequate advice from their doctor, only two out of them exercise at home because they think differently. Eight believe in the therapy’s worth but only three of them exercise. Therefore it can be asserted that benefits of getting physical treatments are poorly promoted due to the lack of awareness of the value of such a treatment by both the doctors’ and patients’ side. Only meds for the cardiac problem are prescribed.

Findings show that people’s belief in the efficacy of the therapeutic measures to slow down the regression of FA and improve the quality of life is low in Lebanon due to the little awareness and communication about the disease; the perceived benefits of use would help patients opt for treatment, in this case, physical exercise which would extend the period of the patient’s independence and mobility. It is unfortunate that many doctors discourage their patients from doing physical therapy despite the visible benefits of such a therapy and its proven efficacy in FA cases outside Lebanon. .

The Literature on other health issues has also shown the importance of perceived benefits.

Tarkang and Zotor (2015) found the. If teenagers perceive the benefits and value of using contraceptive methods in preventing HIV and STDs, then they would use condoms.

An important study to note here is the study done by Tuener, Hunt, DiBrezzo and Jones (2000) on the Osteoporosis Prevention Program (OPP) . The program provided informational and instrumental support including nutrition and exercising classes for a period of one month. It was shown that perceived benefits increased when cues to action, self efficacy in addition to modifying factors were simulated. This may be beneficial in the case of this study on FA. The respondents should not be given or educated on the perceived benefits but they should be given cues to action besides working on reducing resistance factors in their environments to prompt them to perceive of physical therapy and its benefit as a feasible possibilities rather than an improbable impossibility.

5.4 Perceived Barriers

The fourth theme corresponds to the fourth construct of the HBM and is explored through these questions:

1- Did you go to school?

-If yes, what’s the highest level of education you got and how did you manage to move around? What made you quit?

-If not, what were the barriers and why?

2- Employment status: do you work?

    -If yes what and how are you coping?

    -If not, why do you think that is?

3- Is your monthly income sufficient?

4- How are your health needs covered?

5- Do you have a disability card? (from the ministry of social affairs) if yes, how did you know about it?

6- What is the most challenging or difficult thing at home and how do you go through the daily routine?

7- What prevents you from doing therapy?

8- Do you think sharing your experience with someone who has FA might help?

9- Would you get motivated to connect with people with FA

Several factors stop the patients from adopting a healthy lifestyle and active measures; four participants (Mayssa, Rachel, Omar, Nancy) cannot afford the sessions; although they have a disability card from the ministry of social affairs and are entitled to do sessions free of charge in Arcenciel, getting a mean of transportation stands in the way besides the lack of accessibility in building infrastructure and design. Rachel lives in Zahle and doesn’t have anyone to take her to Arcenciel to do physical therapy sessions that she knows how beneficial it is for her. The same thing applies to Nancy who does not have a ride and can’t afford to go by taxi. Mayssa lives on the 5th floor and Omar on the 4th floor and the elevator only works in case there is electricity. Another important reason why Joy, Serge and Omar don’t do physiotherapy is simply because they don’t want to and they lack the motivation and will to do so. However Omar starts and commits then stops depending on his mood. Another factor which is the lack of awareness that physical therapy is beneficial, which applies to Dareen and Lama, Souraya, Omar and Nadine. Moreover, the severe regression that Samar and Nayla suffer from prevents them from taking action.

Kamal and Zeina are the only two participants who do physical therapy. Kamal goes to a physical therapy centre and practices weight exercises for strengthening the muscles. Zeina does the sessions for free in an association funded by Nabih Berri. Sami used to do physiotherapy and hydrotherapy but the doctor and therapists told him he’s not progressing and advised him to stop, so he’s exercising at home. Nancy, Joy, Rachel, Dareen and Lama were not recommended to do physiotherapy either.

When it comes to education and employment, Omar and Zeina are still pursuing their studies. But five (Joy, Mayssa, Saber, sourayya, Omar) went to school and dropped out because it got hard for them to move around, two (Nadine and Serge) quit because others kids were annoying them. Nancy didn’t enrol in university because there were no accessibility and Rachel dropped out of university due to the inaccessible spaces. Samar and Nayla went to elementary school then worked in Sesobel, an NGO that offers a coherent and monitored service of assisting children with disabilities and accompanying their families; until they moved to anta akhi. Sesobel’s partner. Lamia and Claudia graduated from college but no one employed them or assisted them. Kamal graduated from the university and has his own shop; sami has a masters’ degree and works in an advertising company; Joy and Nancy got employed in arcenciel NGO.

So seven dropped out of school and one of university and another one couldn’t enrol while two switched from schools to associations. Two are currently pursuing their studies and four graduated from universities. Only four are working. What can be concluded here is that the exclusion of these individuals from the educational and work fields is a demotivating factor to move forward in life, focus on health to achieve goals and have ambitions. Plus, the lack of education leads to a disinterest to learn and a poor know-how to research any topic.

The findings coincide with the literature. The lack of transportation was seen as an important barrier similar to the study conducted by Tarkang and Zotor (2015) about HIV prevention in Cameroon.

Social norms were seen as a barrier in the study by Siddiqui ,Ghazal, Bibi, Ahmed,and Sajjad (2016) that evaluated public awareness and health beliefs concerning dengue fever. In this study, 2 out of 15 respondents quit their education because they felt socially awkward. It is unfortunate that most of the Lebanese schools and universities are not equipped, neither nor in terms of personnel, to accommodate cases of FA.To sum up, based on the interviews conducted, individuals afflicted with FA are facing different barriers to be educated as a first and then carry out with physical therapy such as perceived complexity, cost, lack of support and transportation and lack of motivation.

5.5 Cues to action:

This theme accounts for the fifth construct of the HBM, which is tested through these questions:

1- What do you think would have influenced the awareness level in Lebanon?
2- Have you seen, read or heard any type of media message related to FA in Lebanon? If yes, please specify the type of media and message
3- What type of media would be, in your opinion, the most effective for spreading awareness about FA?

4- Do you think that expressing your feelings and sharing your concerns to the media would help?
5- Who do you think can provide you with physical and technical support when dealing with FA?
6- Who do you think can provide you with emotional support when dealing with FA?
7- What do you think should change in our country so you could have a better quality of life?

None of the participants or their parents have seen any media message or information related to FA in Lebanon. All of the participants affirmed that media can help spread awareness about FA in Lebanon since FA is unfamiliar. Five suggested that TV is a powerful communication tool, five suggested social media. Kamal recommended advertising in cinemas and reality TV. He also recommended showing how people with FA live in Lebanon compared to those with FA in Western countries to emphasize the depravity that FA patients in Lebanon suffer from.. Sami recommended advertising campaigns for the disease to educate society and the government and medical conferences to share knowledge and orientation for individuals to help them learn how to live and cope with FA independently. Omar suggested community gatherings for FA.

Mrs Roula Najm, anta akhi General manager believes mindset training should be given to help people cherish their lives regardless of their disability. Nadine suggested a talk show or educational program about FA while Sourayya said that parents are the ones who need awareness the most. Saber is the only participant who doesn’t care about awareness in general; he just wants help on a personal level. Nancy, Omar and Nadine think an organization for NGO will help spread awareness about it.

When asked what can be changed so they have better qualities of life, ten emphasized on the need for new infrastructure and more accessible public places and a shift in the society’s mindset regarding disability and their right for education and work. Six suggested the founding of an NGO for FA in Lebanon for social integration as well. Nadine’s wish was: “if only there is an NGO that would organize hangouts and activities, I feel lonely and left out”. Zeina’s mother called for proper medication and consultations and Serge thinks that doctors should be given awareness training as well. Saber, Dareen and Lama think that society lacks humanitarian values.

As for emotional support, living with FA gets a bit bearable with the support of family and friends and faith. While arcenciel and the ministry of social affairs through giving away semi-free wheelchairs and physical therapy sessions provide technical and physical support.

Briefly, cues to action in Lebanon do not exist and each of the sixteen participants suggested what they believe to be good strategies to activate their readiness and that of society’s.

> However, based on the research about international FA communication, cues to action for FA take many forms in Europe, Australia, USA and Canada through

blogs, social media, articles, books, informational websites, medical journals, press releases and most importantly research associations and non-governmental organizations.

The HIV prevention study in Cameroon by Tarkang and Zotor (2015) asserted that cues to action such as providing how-to information, promoting awareness, reminders and events motivating and educating an individual for condom use serve as the catalyst for taking action.

Based on the results of the “Design and Implementation of an Osteoporosis Prevention Program, Tuener, Hunt, DiBrezzo and Jones (2000) state that cues to action in addition to other factors, affected women’s perceptions and behaviour. These cues to action consisted of informational and instrumental support including nutrition and exercising classes provided by the program in addition to hand-outs, illustration and information from the `national Osteoporosis Foundation and American College of Sports Medicine given out to participants.

Romano, Scott & Smith (2014) suggested that the Village Heart BEAT Building Education and Accountability program was a success in reducing obesity amongst African American and Hispanic population in the US through different cues to action; they consisted of free courses and classes of weight management, group exercises classes, water fitness, healthy living seminars, health coaching, monthly team challenges and more.

In Lebanon, the cues to action should target the different groups involved in FA. These groups are the patients, the doctors and healthcare workers, the parents and family and the society. The cues to action differ for every group. While the first three may require educational, training, and lifestyle sessions in differing degrees, the fourth, which is society mainly requires awareness campaigns. These cues to action would help create a real support group around the FA patient and will help turn the FA patient into an individual that is more aware and more accepting of their condition.

5.6 Self-efficacy:

This theme refers to the sixth construct of the HBM, which is associated with the following questions:

1- If you were told about community gatherings for FA, would you join?
2- Do you think you can actually (physically) join? If yes, who would help you join? If not, what would stop you from being joining?
3- If there is a facility that provides you with physical and psychological care, would you subscribe? And what might stop you?
4- If you have the opportunity to treat your symptoms knowing it doesn't cure you, do you consider yourself motivated and determined to go through with it?
5- If there are trainings available and job opportunities, would you apply and why?
6- Do you think that you can make a vital change to improve your own life?
7- Do you think that can help others with FA to improve their lives?

Five participants (Joy, Sourayya, Dareen, Lama and Serge) don’t have the motivation or energy to get treated and don’t even believe that it is beneficial for them; they just gave up on life. Omar gets treated and believes he can do it but he’s going through a depression where he is rejecting himself and his case. However eight of the participants (Nancy, Mayssa, Zeina, Rachel, Saber, Kamal, Nadine and Sami) are willing to change their lifestyle and join a facility that would provide them with physiotherapy and psychotherapy sessions. Samar and Nayla were not very responsive and according to the GM of anta akhi; they are being taken care in the best way possible. Although Nancy, Mayssa, Zeina, Rachel and Saber believe they can take therapeutic measures if given an opportunity, they have many restrictions that stand in their way such as means of transportation and caregiver to assist them. In the case of Mayssa, she is constrained by the electricity since she lives on the 5th floor and the elevator only works if there is electricity.

As for FA community gatherings, only Joy and Nancy are not interested in joining; Joy is too careless and Nancy is scared of meeting people whose FA symptoms are worse than hers. As far as it concerns helping others with FA improve their lives, “Samar and Nayla are live testimony of inner peace and acceptance”, said Mrs.Najm. Five (Mayssa, Rachel, kamal, Nadine and Sami) have high morals and are confident in making a positive change in their lives as well as for others’. Mayssa, But Dareen, Lama and Nancy don’t know if that is possible. Joy, Omar and Serge don’t think they can; Souraya, Zeina and Saber answered hesitant yeses.

To sum up the eight who are confident in their ability and have self-efficacy to adopt therapeutic measures are the ones who are getting treated; however three of them stopped due to external limitations. The same applies to most of the findings of the literature: Tuener, Hunt, DiBrezzo and Jones (2000), showed that exercise self-efficacy is one of the strongest predictors of women's engagement in the recommended levels of weight-bearing exercise in the Osteoporosis Prevention Program. Results have shown that those who do not engage in these exercises don't believe they can.

However, through the Adolescents' Fertility Control study conducted by Eisen, Zellman & Mcalister, (1992), within the program's objectives to increase knowledge of and motivation for abstinence or contraceptive use, it was found that self-efficacy was not mentioned as a powerful influence on teenagers' behaviour.

Self- Efficacy is the first step towards making a change in life of individuals with FA. The ones who trust their capacities and strength are the ones adopting therapeutic measures or at least who are searching for ways to change their life. However barriers stand in their way so either they try to go around them or stay stuck in their bodies.

When visiting Mayssa, her mother told me that she refuses to use the wheelchair at home to go to the restroom; she would crawl if she has to but she wants to stay active. And then she tells me: "I can stand up, let me show you". With a lot of efforts and support from her mother she stood up proudly and added with teary eyes: "if only there is a solution for the electricity, I would go back to physical therapy, school and activities".

5.7 Modifying factors

This theme accounts for a construct that has been added to the original HBM that was found to affect people’s perceptions and behavioural change. Some variables were deducted by observation of the environment and others either by directly asking or resulting from other questions. Participant’s gender, environment, culture and traditions, personality traits and attitudes were observed and questions concerning their age, education and occupation, past experiences, knowledge and motivation were asked indirectly depending on the context of the discussion while testing other constructs. For example, education and occupation are asked in the perceived barriers, relatives’ experiences with FA in the perceived susceptibility, awareness-knowledge about FA in the perceived benefits and motivation of the participants in the self-efficacy section.

When it comes to education and employment, seven dropped out of school and one of university and another one couldn’t enrol while two switched from schools to associations as discussed in the perceived barriers. Two are currently pursuing their studies and four graduated from universities. Only four are working. It can be concluded that the level of education is low, which affects knowledge in general and consequently limiting the means of researching and assimilating information about FA. The level of employment is low as well, which means the integration in the work field is poor. This influences individuals’ social and financial aspects of life. Twelve of the participants financially rely on their parents or relatives for a living and five families have very poor conditions and two live in anta akhi. Therefore the perceived severity about FA and its consequences are affected as well as perceived benefits of all kind of therapies.

FA is common among Omar’s relatives and his parents are cousins. Marcel and Nayla are sisters, same as Nancy and Joy, and Dareen and Lama. Nayla(37), Dareen (39) and Nancy (27) are the youngest. Therefore the eldest sisters and the relatives’ experiences having been diagnosed with FA increased the perceived susceptibility and severity of the younger sisters and Omar’s mother.

Ten out of the sixteen do not follow up medical research and news about FA; the remaining six get their information from the internet and new through FA websites. Whereas six were advised by their doctors not to do physical therapy and that it is pointless since the disease is regressive, only three did not trust the doctor’s advice. Therefore, knowledge is very low fon the patients and the doctors’ sides. And cues to action in Lebanon do not exist which affect as well the low perceived severity and benefits.

Five participants (Joy, Sourayya, Dareen, Lama and Serge) don’t have the motivation or energy to get treated and don’t even believe that it is beneficial for them. When I visited Omar, he didn’t come out of his room and slammed the door after a while and left so I conducted the first interview with his mother. He called me the second day and apologized and I interviewed him over the phone; he is going through a depression, he rejects his case, starts then stops therapy depending on his mood. It can be noted that the ones who lack motivation, also lack self-efficacy.

The psychological profile and personality traits of a person play an important role in determining that individuals’ behaviour. I went to arcenciel to interview Joy and Nancy; at first, only Joyce showed up and Pamela claimed she was busy; so I insisted I want to interview them both separately. When she showed up, she admitted she doesn’t want to see me; while everyone accused her of being arrogant, she explained to me that she is very sensitive and was afraid that seeing someone with the same disability as her or worse might upset her. So I asked her how she felt after meeting me , she told me she felt relieved and she was looking up to me and felt quite the opposite. She got very emotional in the middle of the interview and started to cry when she was talking about the lack of support and care in her family. She feels neglected and is obviously fed up with her sister’s jealousy. Nancy is on a wheelchair, she can wheel, she walks at home and talks well. However she is not happy, needs privacy and wants to do something out of her life but she can’t she feels trapped and wants a cure. When I asked her if she has cardiomyopathy, she laughed and said: “I wish I did so I would die peacefully”

Joy looks peaceful but actually she gave up on life, lacks self-confidence and doesn’t care about anything. She just wants to sleep; that is her overall attitude. She doesn’t even go to church because she hated how everyone stares at her. Her case is very advanced, but she doesn’t want to know anything about the disease or to take any kind of action.

Dareen and Lama are very welcoming and sweet. Both finished their studies but they don’t work. They have speech, hearing, excessive fatigue and weakness problems.

They’re on wheelchairs but can’t wheel. They couldn’t believe I have FA. To them FA equals total immobility and they don’t believe in therapy. Zeina was very shy and embarrassed; at some point, she cried so the interview was with the mother. She uses the walker, and mainly the mother told us she drags her when she wants to go out instead of using the wheelchair.

Serge lacks motivation and love of life. He is in a chronic depression; it’s been over than 15years. He wants nothing but to be cured. He blames God and family for his condition. He asked me to close my eyes and when I did, he told me: “the darkness you see when you close my eyes is all I see when I open them.”. His mother affirmed to me that his brother and sister are way more educated, but Antonio, Serge’s brother, is smarter he just doesn’t have any will. He is neurotic most of the times and he even causes depression to his brother.

Sourayya seemed a little shy, bored and uninterested; she contradicted herself a lot especially during the self- efficacy questions; her attitude says one thing and her words another. Saber is very stubborn and negative and is highly influenced by his father who doesn’t believe in him.

However, Rachel, Mayssa, Kamal and Sami have great positive attitudes towards life and family support. Sami grew up abroad in Austria, Germany then Belgium with his parents, where everything was accessible and he was seen as a valuable person regardless of his handicap unlike Lebanese society’s perception where they devalue the person with a handicap.

To sum up the factors are affecting the respondents’ enthusiasm for life, their hope in delaying the regression of the disease and their general attitude toward themselves and the society around them, are many. The factors, from the lack of education about the disease to the lack of information, alongside the lack of actual physical, financial and emotional support, become crippling to the FA patients, who are, in general, feel alone in a battle they can never win on their own.. The literature findings confirm the importance and influence of the modifying factors.

In the Cameroon HIV Prevention study, Tarkang and Zotor (2015) asserted that Structural and demographic variables such as race, age, culture, knowledge, influence as well the individuals’ preventive behaviours.

The sexuality education program conducted originally by Eisen, Zellman and McAlister (1992) showed. Modifying factors such as religious

The modifying factors surrounding an FA patient, then, can make a difference in whether that patient gives up on life and lives for years in depression or is able to find hope and a reason to progress and accomplish despite the odds.

In conclusion, the seven themes, investigated through the Health Belief Model, provide answers to the research questions of the thesis and offer a better understanding of the health behaviour of people affected by FA in Lebanon and the consequences of the lack of information about it.

First, the low perceived severity about the seriousness about FA, the low perceived benefits of taking therapeutic measures and the non-existent cues to action slow down the willingness of taking action towards FA. The low Perceived severity about FA’s consequences and the existence of treatments, and the perceived benefits of physical therapy, counselling, speech therapy are mainly affected by the lack of diffusion of information and the low awareness level in Lebanon; a considerate number of the participants only rely on their doctors’ explanation when diagnosed, which in turn is very limiting since there is a lack of knowledge about FA from the medical perspective as well. Any strategy that can prompt behavioural and even educational change does not exist. In other terms, the willingness of individuals with FA who are disoriented and disinterested to acknowledge the consequences that FA engenders to get prepared to adapt and fight the regressive symptoms is not activated due to the lack of cues to action.

Second, the high perceived barriers to getting treatment include the perceived complexity and the cost of the physical therapy sessions, lack of support and transportation and lack of motivation. This construct is influenced by modifying factors such as low educational level and financial incapability that stand in the way of knowledge and awareness about FA. Participants’ psychological, socio-demographic, socio-economic, culture and knowledge factors impact their knowledge about FA and motivation to take action.

Third, what is noticeable is that the eight participants who have high self-efficacy and confidence in their ability to adopt therapeutic measures are the ones who are getting treated; however three of them stopped due to external limitations. Judging from the results found in this study, it would not be unlikely that those who have stopped treatment, may like the others, eventually lack self-efficacy and surrendered to depression.

Throughout this research, the HBM is found to be very useful in comprehending health behaviour of people living with FA. An education and prevention program must be developed to promote health awareness and knowledge, induce cues to action, and increase perceived severity, benefits, and self-efficacy while decreasing perceived barriers.

This study has been the most intense experience I have ever been through, it evoked in my whole being feelings of anger and rebellion against an ignorant mentality and an indifferent country, but followed by an iron will and unstoppable determination to keep fighting FA and facing every challenge that comes my way and most importantly act on paying it forward and giving back an opportunity to lead a valuable life through medical, physical, emotional and psychological support to the unprivileged ones who were left alone to deal with FA. This thesis is the starting point of a long-term mission that hopefully would change lives of people living with FA and a reminder that no matter how rare a disease may be, hope should never be.

Chapter VI: Limitations and Contribution to Knowledge

6.1 Limitations

The HBM has been very useful in terms of understanding health behavior of individuals with FA, however it is not very accurate since it does not account for environmental factors that play an important role in a country like Lebanon and consequently influence modifying factors that stand in the way of people taking action that are beyond the control of patients.

Moreover, the poor communication about FA in Lebanon and lack of academic studies about FA in Lebanon were some of the obstacles faced. All of the literature findings covered were foreign studies done on different health issues and it was hard since Lebanese respondents’ culture and environmental factors are different from foreign ones. One last limitation is the transparency and honesty of the interviewees. Since the topic of the study is very delicate and personal, some might have not been completely transparent in their answers and reflections especially when conducted by the students who do not suffer from FA. Their answers did not match when I visited two of them later on for a personal project.

6.2 Contributions to knowledge

This thesis constitutes the first research conducted about FA communication in Lebanon; the patients’ health behaviour findings are considered crucial to make contribution to the lack of knowledge in this field. Through this study, a comparative analysis about the communication efforts was done abroad and in Lebanon aiming to comprehend the consequences of this silence on patients and understand their health behaviour and what is stopping them from taking therapeutic measures. The results helped depict the causes of the non-existent dealings with FA and hopefully gather these people all together under one non- profit organization as a first in Lebanon to fight together for a better future and a dignified quality of life.

APPENDIX III

THE INTERVIEW QUESTIONS

The interview questions are divided into the different concepts of the Health Belief Model

Concept: 1. Perceived susceptibility

- **One's opinion of chances of getting a condition**

1- At what age did the symptoms start?

2- What kind of symptoms did you first experience?

3- Do any of your family members experience this condition ?

4- Did you know that you could be susceptible to FA

5- What kind of doctor did you consult and why?

6- What is your doctor's diagnosis?

7- Before getting tested for FA, did you have an idea what it was?

[yes] [no]

If yes, how?

[Doctor's assumption] [your own research] [you know someone affected by FA]

Other, specify

Concept: 2. Perceived severity

- **One's opinion of how serious a condition and its consequences:**

1- What are you diagnosed with? What are the symptoms that cause you discomfort?
2- Are they evolving? Any idea how to slow down the regression?
3- Do you follow up exams every now and then?
4- Did you have an interest in learning more about your condition? If yes, what sources did you consult with (doctors, family, friends…)
5- At what age were you diagnosed?
6- What kind of assistance do you need? (technical, human)

Concept: 3. Perceived benefits

- **One's belief in the efficacy of the advised action to reduce risk or seriousness of impact:**

6- Do you follow up medical research and news about FA?

[yes] [no]

If yes, how?

[you ask your doctor] [internet search] [social media] [people in the medical field] [you talk to other patients

7- Are you on medication and are there measurements you take for treatment?

[yes] [no]

If yes, specify

[physical therapy] [hydrotherapy][gym workout] [exercising at home] [psychotherapy] [spiritual guidance] [vitamins]

8- How and where do you get treated and if you don't why not? Can be used in the perceived barriers

9- Who is your doctor/does he follow up with you/ what is his advice?

10- Do you think that you will get a long term benefit from the preventive measurements you are taking?

a. No benefit

b. Little benefit

c. Moderate benefit

d. Considerable benefit

Concept: 4. Perceived barriers

- **One's opinion of the concrete and psychological costs of the advised action:**

10- Did you go to school?

-If yes, what's the highest level of education you got and how did you manage to move around? What made you quit?

-If not, what were the barriers and why?

11- Employment status: do you work?

-If yes what and how are you coping?

-If not, why do you think that is?

12- Is your monthly income sufficient?

13- How are your health needs covered?

14- Do you have a disability card? (from the ministry of social affairs) if yes, how did you know about it?

15- What is the most challenging or difficult thing at home and how do you go through the daily routine?

16- What prevents you from doing therapy?

17- Do you think sharing your experience with someone who has FA might help?

18- Would you get motivated to connect with people with FA

Concept: 5. Cues to action

- **Strategies to activate readiness:**

8- What do you think would have influenced the awareness level in Lebanon?
9- What type of media would be, in your opinion, the most effective for spreading awareness about FA?
10- Have you seen, read or heard any type of media message related to FA in Lebanon? If yes, please specify the type of media and message
11- Do you think that expressing your feelings and sharing your concerns to the media would help?
12- What do you think should change in our country so you could have a better quality of life?
13- Based on your experience, do you believe doctors and therapists are helping you somehow?

14- Do you think that expressing your feelings and sharing your concerns to the media would help?

15- What do you think might offer you support?

Concept: 6. Self- efficacy

- **Confidence in one's ability to take action:**

8- If you were told about community gatherings for FA, would you join?
9- If there is a facility that provides you with physical and psychological care, would you subscribe? And what might stop you?

10- If you have the opportunity to treat your symptoms knowing it doesn’t cure you, do you consider yourself motivated and determined to go through with it?

11- If there are trainings available and job opportunities, would you apply and why?

12- Do you think that you can make a vital change to improve your own life?

13- Do you think that can help others with FA to improve their lives?

Modifying factors:

- **psychological, socio-economic and socio demographic variables that affect perceptions**

  Gender of the patient, his age, where he lives, education, occupation and a small description and impression of him.

APPENDIXES I & II ARE ATTACHED IN THE EMAIL

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