The lived experiences of people with mental illness and the impact on their families

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A dissertation submitted in partial fulfilment of the requirements of the Master of Arts in Disability Studies

Disability Studies Unit
Faculty for Social Wellbeing

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DECLARATION

30th April 2017

I, the undersigned, hereby certify that this dissertation entitled ‘The Lived Experience of People with Mental Illness and the Impact on their Families’ is an original study carried out by myself and the interpretations and conclusions drawn herein are a result of my own work, unless otherwise acknowledged by citation. This study was performed under the supervision of Dr Anne-Marie Callus and with the advice of Mrs. Catherine Vassallo.

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Dr. Anne-Marie Callus
Principle Supervisor
DEDICATION

Dedicated to my beloved family,
For their constant love and support

“Mental illness is nothing to be ashamed of,
but stigma and bias shame us all”.
Bill Clinton
ACKNOWLEDGMENTS

My heartfelt thank you goes to my supervisors Dr. Anne-Marie Callus (principal supervisor) and Mrs. Catherine Vassallo (advisor), for their invaluable assistance, time and impressive patience and constant encouragement throughout the research process. Through their expertise, they have inspired me and I am truly grateful to their contribution to this study.

I owe a special thank you and appreciation to all the participants who accepted to take part in my study and shared their valuable stories and experiences. This research would not have been possible if it wasn’t for their priceless contribution, cooperation and support.

I also sincerely thank my family for their unfailing curiosity, encouragement, unending love and support. They have believed in my potential to carry out this study and offered me a shoulder to cry on when times got tough.

Above all, I thank God for giving me the strength and courage to carry out this study and for His guidance all the way.
ABSTRACT

Approximately one out of four people worldwide experience mental illness at some point in their life. In past times, mental illness was associated with demonic possessions. Nowadays people with mental illness are more accepted in society even though their illnesses are still considered as a taboo subject and they are often faced with stigma.

This study explored the lived experience and perspectives of people with mental illness and their families. In addition to this, the study also explored the main barriers that the participants face in society. The main conceptual frameworks used in the study were the social model of disability and interpretative phenomenology.

A qualitative approach was used in this study. The research was carried out in a Maltese context. Participants were recruited through three NGOs working in the field of mental illness. They were selected using purposive sampling. Four people with mental illness and four family members, chosen by the person with mental illness him/herself, took part in this research. Each participant was given an information letter, either in English or in Maltese according to their preference, about the study. Semi-structured interviews were used and data was analysed using an interpretative phenomenological approach (IPA). IPA draws from three influences which are phenomenology, hermeneutics and idiography. Using IPA in this study enabled the researcher to get a closer look at the participants’ lived experience.

The single most prevalent factor that emerged from the interviews was stigma. It was the most dominant barrier that was experienced in any aspect and lived experience of people with mental illness. When referring to people with mental illness and their families, the concepts of Dasein and Mitsein by Heidegger were used. Dasein referred to people with mental illness whilst Mitsein referred to the family members. The being-in-the-world of people with mental illness is engulfed by stigma. The family members indicated that their lived experience is more about care (Sorge) and empathy towards their relative with mental illness. Rather than experiencing barriers themselves, the family members were more affected by how others treated their relative with mental illness. Since stigma was always rebounding back to the person with mental illness, it was compared to the strings of the Yo-Yo.
While this study has contributed results similar to the literature review about the lived experience of people with mental illness and their family members, further emancipatory research is required especially when it comes to services for the family members. Findings showed that the transition of services from Mount Carmel Hospital to Mater Dei Hospital might be one projecting possibility, that is one of several possibilities that decrease the stigmatising way how the public views mental illness and aid the lived experience of people with mental illness and their families to be less negative. The media is another projecting possibility as it can be used to provide awareness and education about mental illness.

**KEYWORDS**: mental illness, lived experience, IPA, phenomenology, social model of disability, Dasein, Mitsein, Sorge
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Chapter 1

Introduction
CHAPTER 1: INTRODUCTION

1.1 Preamble

It is estimated that one out of four people worldwide may experience a mental illness at any point in time. It is also estimated that two-thirds of the people who have a mental illness do not seek help or treatment due to stigma, discrimination and neglect (WHO, 2001). As stated in the World Health report in Geneva (2001), “[w]here there is neglect, there is little or no understanding. Where there is no understanding, there is neglect”.

1.2 The Context

The World Health Organisation (WHO, 2003) describes mental health as “a state of well-being whereby individuals recognise their abilities, are able to cope with the normal stresses of life, work productively and fruitfully, and make a contribution to their communities” (p. 7). In contrast, when having a mental illness, the person may experience a combination of abnormal thoughts and emotions, changes in behaviour and difficulties in relationships with others (WHO, 2016).

In ancient times, symptoms resulting from mental conditions were considered as demonic possessions. It was recently that physicians and professionals became involved with mental illnesses rather than priests, whom the latter were given more importance in past times. (Mondimore, 1999).

Nowadays, approximately 450 million people worldwide have a mental illness. Out of these 450 million people, 150 million persons experience depression at a certain point in their lives and almost 1 million commit suicide yearly. Approximately 25 million people are diagnosed with schizophrenia, 38 million with epilepsy and over 90 million have an alcohol/drug disorder which is also considered as being part of mental illness (WHO, 2003). The World Health Organisation report (2003) states that burdens of mental disorders are not only faced by the person with mental illness him/herself, but they often present a burden on the family as well. In fact, the report states, “[t]he extent of the burden of mental disorders on family members is difficult to assess and quantify, and is consequently often ignored. However, it does have a significant impact on the family’s quality of life” (p. 12).
The impact of stigma effects the quality of life of a person with mental illness and even their families as it leads to decreased opportunities in employment, diminishes satisfactory health care and limits the person to interact in society (Corrigan & Watson, 2002). In their study, Corrigan & Watson identified two types of stigma which are public (structural) stigma and self-stigma. Public stigma refers to the negative attitudes and discrimination that the public has about people with mental illness, whilst self-stigma, as quoted by Corrigan & Watson (2002) “is the prejudice which people with mental illness turn against themselves” (p. 16). This self-stigma comes about as people with mental illness believe the idea that they are less valued in society because of their mental illness. The effects of stigma will be discussed in more detail in Chapter 2.

Mental health disorders account for up to 60 per cent of disabilities, which is quite a high expectancy when compared to other impairments (Jagger et al, 1998). There are several mental health disorders that are diagnosed by professionals in the United States (Grohol, 2014) and in Malta in 2014, it was estimated that around 30,000 citizens have chronic depression (Malta Independent, 2014).

There may be no external factors that trigger the mental illness. Several factors however, may lead to mental disorders including poverty, chronic illnesses, neglect and exclusion, being part of a minority group and discrimination (WHO, 2013). In addition to this, the rate of disability and mortality is found to be higher in persons with mental illness (WHO, 2013). In fact people who have depression and schizophrenia have a higher chance, 40-60% to be exact, of dying prematurely than when compared to the general population (WHO, 2013).

Mental illness was not always considered as a disability, even in Malta until 1997 (WHO, 2011). However, it is in fact a disability and this is clearly noted in Article 1 of the Convention on the Rights of Persons with Disabilities. The British Equality Act, and the Equal Opportunities (Persons with Disability) Act (2000), in Malta also acknowledge mental illness as a disability. More about these Acts will be discussed in Chapter 2.

The Mental Health: Evidence and Research team (MER) is a team which was set up by the WHO. Its main focus is to minimise the burden and barriers that may be caused by society on people with mental illness. It works on what is required and what is currently present in the health system and in society, in order to decrease these barriers and promote information about
mental health. This is translated into several projects including Atlas, Mental Health in Emergencies and World Health Organisation Assessment Instrument for Mental Health Systems (WHO-AIMS). The latter is a tool developed by the WHO which collects important information about a country’s mental health system (WHO, 2015).

1.3 Research Purpose

The study is entitled 'The lived experiences of people with mental illness and the impact on their families'. I have chosen this subject for my dissertation as research about people with mental illness and the impact on the family is scarce and their role in society is not given much importance. In addition to this, due to several barriers that these disabled people and their families encounter, it would be of utmost satisfaction for me if I can try and make a difference in these peoples' lives by increasing awareness and health promotion to try and minimise these barriers. Having experienced mental illness in my family myself, has motivated my interest in this topic.

The aim of this study was to explore the lived experience and perspectives of people with mental illness and their families and the barriers that they face in society. Through this research, I am hoping that people with mental illness and their families will be granted an opportunity to be heard as, in my opinion, mental illness is still being considered as a taboo in society. The study specifically explored the following research questions:

- What are the experiences and the perspectives on life of people with mental illness?
- What are the experiences and perspectives on life of family members of people with mental illness?
- What barriers do people with mental illness and their family members face in society?
- What support needs do they identify for themselves?

1.4 Conceptual Framework

The study viewed people with mental illness and their family members as the experts about their lived experiences. The social model of disability and phenomenology were therefore the conceptual frameworks used in the study, with interpretative phenomenological analysis (IPA) being used as the research methodology. Being a qualitative study, the paradigm of
interpretivism was adopted, which has greatly influenced the social sciences, and therefore enabled a better understanding of the social world of people with mental illness and their families. They can be represented as being human actors who are constructing their social reality through their lived experiences (Chowdhury, 2014). As cited in Chowdhury (2014), interpretivism “refers to the approaches which emphasise the meaningful nature of people’s character and participation in both social and cultural life” (p. 433).

1.5 The Social Model of Disability

The process of reformulating disability from a medical point of view to a more social one commenced in the 1960s and 1970s in Britain. With reference to Hunt’s book (1966) *Stigma: The experience of disability*, allowances for people with disability including dependent children where poor when compared to foster children for instance. People with disability are also affected by stigma that is imposed on them, as society views them differently from others. Hunt explained that people with disabilities do not want to be treated as if their disability does not exist but they want their disability to be acknowledged and accepted by non-disabled people and by the authorities (Hunt, 1966). Eventually, individuals with disability, activist groups and academics started protesting against institutions, their exclusion from employment and the opportunity to earn a wage and against poverty which was imposed on them (Siebers, 2008). The social model of disability has been described as ‘the big idea’ of the British disability movement. These struggles gave rise to new ideas about disability, in fact the Union of the Physically Impaired Against Segregation (UPIAS), came up with an important statement about the concept of disability from a social perspective. As, UPIAS (1976) stated “[Disability is] the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have impairments and thus excludes them from the mainstream of social activities” (p. 22).

As explored further in Chapter 2, when talking about disability, oppression, inequality, stigma and discrimination are among the first few words that comes to mind (Oliver, 1990). Disability was associated with the individual model, the medical model or the tragedy model of disability. When the UPIAS was formed in 1974 by Hunt, Finkelstein and Davis, disabled activist Mike Oliver, who later joined the union, formed the social model of disability as we know it today (Oliver, 1990). The social model of disability does not deny the disability but instead it associates the disability within our society. People with disability talks about isolation and
argues that they should be treated the same as non-disabled people. As quoted in Hunt’s Stigma: The Experience of disability (1966), “[t]he partially disabled person ... needs to become part of "normal' society and not isolated among his own kind” (p. 2). This segregation was visible in leisure activities, schools and in the workforce (Hunt, 2007). When lacking appropriate services and accessibility, it does not only affect one person, but affects people with disability as a group, as in the case of people with mental illness. This is all due to the presence of stigma, discrimination and barriers that are found within society as will be seen in more detail in Chapter 2.

Perhaps, as Shakespeare (2002) stated, “if the social model argument was pushed to its logical extreme, we might not see impairment as something which we should make efforts to avoid” (p. 13), as disability is defined as the social responses rather than by what type of impairment the person has (Shakespeare & Watson, 2002). There is an interlink between the social responses and the lived experience of people with disability, who in this study were people with mental illness. The impairment is not necessary a tragedy and here the social model comes into play, as one is not focusing on the impairment. If the social responses are not on the negative side, then the lived experiences of people with mental illness are not necessary on the downside. It is therefore something that can be used to minimise the stigma that is imposed on mental illness in general, rather than seeing mental illness only as a tragedy.

1.6 Phenomenology

Phenomenology was the other conceptual framework used in this study as mentioned earlier. It is based on the work of the German philosopher Edmund Husserl, and was later developed by Heidegger, among other philosophers. One experiences a phenomenon through the process of consciousness both through individual and shared meanings and experiences (Larkin, Watts & Clifton, 2006). For Husserl, phenomenology entails the careful assessment of human experience. His main interest was finding a way by which someone comes to know his/her own experience by stepping out that everyday experience which he calls it the ‘natural attitude’ (Smith, Flowers & Larkin, 2009). This will be further discussed in Chapter 3. As Smith, Flowers & Larkin (2009) stated, Husserl also speaks about the lifeworld which is “the taken-for-granted, everyday life that we lead” (p. 15). This provides an objective or a scientific way to understand the experiences. Through his works, Husserl aids researchers who use an interpretative phenomenological approach to focus on reflection where “[h]e sets the agenda
for the attentive and systematic examination of the content of consciousness, our lived experience, which is the very stuff of life” (p. 16).

Martin Heidegger started his philosophical career as a student of Husserl and developed the idea of phenomenology even further. He focuses more on hermeneutics where there is more focus on the individuals’ meaning of lived experiences (Creswell, 2007). This will be further discussed in this chapter and in Chapter 3. Heidegger criticised Husserl’s idea of phenomenology as being too philosophical and too theoretical (Smith, Flowers & Larkin, 2009). In his work *Being and Time* he focused on the concept *Dasein* (which literally means ‘there-being’) and argued that this concept was largely neglected in Western philosophy. In this study *Dasein* referred to people with mental illness. In English, *Dasein* is translated into being-in-the-world or in other words existence and as cited by Moran (2000), “the world of *Dasein* is a with-world” (p. 242) Heidegger does not ignore the experience of the ‘other’. He claims that it forms part of the experience of being-in-the-world because the world is always shared with others (Moran, 2000). He refers to this as *Mitsein* where in this study, it referred to the family members of people with mental illness. There is also the element of care or in other words *Sorge* when looking after a person with mental illness. The natures of *Dasein*, *Mitsein* and *Sorge* will be further discussed in Chapter 4. Another phenomenological concept adopted by Heidegger is *intersubjectivity* which refers to “the shared, overlapping and relational nature of our engagement in the world” (p. 17). This concept aims to develop an ability to communicate and make sense of one another through common lived experiences (Smith, Flowers & Larkin, 2009). How these concepts will be used in this study will be discussed in Chapter 3.

From the philosophical framework of phenomenology, the idea of hermeneutics which is defined as the science of interpretation, was developed. Heidegger pointed out that through this theory of interpretation there is access to time and engagement with the world (Smith, Flowers & Larkin, 2009) therefore it presents an important insight for IPA research as it provides access to the lived experiences in this case of people with mental illness and their family members. As cited in Pietkiewicz & Smith (2012), “[a]ccording to hermeneutics one needs to comprehend the mind-set of a person and language which mediates one’s experiences of the world, in order to translate his or her message” (p. 362). This is why hermeneutics is used in IPA as the researcher tries to understand and interpret the participants’ experience. As will be discussed in Chapter 3, there is a double hermeneutic or dual interpretation as the participants
are first making meaning of their world and then the researcher tries to make sense of that meaning (Pietkiewicz & Smith, 2012).

1.7 Conclusion

This study explored the lived experiences of people with mental illness and the impact on their families, through a qualitative approach. Chapter 2 of the dissertation is the literature review which looks at numerous empirical studies about the experiences of people with mental illness and family members. The research design together with the methodology and frameworks will be discussed in Chapter 3. The research findings and interpretation of results will then follow in Chapter 4. Chapter 5 will include the conclusion together with the strengths and limitations of the study and puts forward some recommendations for further studies.
Chapter 2

Literature Review
CHAPTER 2: LITERATURE REVIEW

2.1 The Literature

Mental illness including bipolar disorder, depression and schizophrenia often have a devastating impact on both the person and his/her family. People with mental illness are nowadays living in the community due to the deinstitutionalisation process, and mainly receive their support from family caregivers (Fenech & Scerri, 2014). The transition from being an in-patient in a psychiatric hospital to living in a community has been an important step in the recovery process of people with mental illness (Gostin, 2008). According to Browne & Courtney (2005), living in a community aids in reducing stigma and improve the quality of life both of the person with mental illness and even of their family members.

This literature review will focus on the lived experiences of people with mental illness and their families from published work, retrieved from various databases. The themes that will be explored in this chapter relates to both people with mental illness and also their family members. Mental illness is considered as a disability. This is in accordance to the UNCRPD and will be further discussed in section 2.3. People with mental illness encounter several barriers as will be seen in this chapter which includes stigma, discrimination, labelling and barriers in employment. Mental illness leaves an impact on the quality of life of the family members as well, as they would need to make adaptations in their life. They also find themselves faced with the social barriers of stigma and labelling as will be seen later on in this chapter. The first section of the literature review will commence with the prevalence and statistics about mental illness and will eventually include information about mental health support in Malta, as this study is set in a Maltese context.

2.2 Prevalence and Statistics

It is quite difficult to determine the exact number of people who have mental illness. Even though various surveys include questions about mental health, few of them gives the exact prevalence of diagnosable mental illness (Bagalman & Napili, 2015). According to the 2013 National Survey of Drug Use and Health (NSDUH), the prevalence of mental illness in the United States was 18.5% in people over 18 years of age (Bagalman & Napili, 2015). In another study by the National Alliance of Mental Illness (NAMI), 1 in 4 adults amounting to 61.5
million Americans, has some sort of mental condition. The approximate percentage of youths between the age of 13 to 18 who have severe mental conditions, is 20%, whilst those between ages 8 to 15 amounts to 13% (NAMI).

In Malta it is also difficult to have a clear cut number on the prevalence of mental illness, since little information is provided (EU WHO, 2005). According to the Malta Census 2011, there are approximately 7045 people who have mental illness in Malta. People ranging between 50 and 60 years of age seem to have a higher expectancy of mental illness. Youths aged between 11 to 20 with mental illness amount to 1.9%. In the Malta Census, there isn’t a considerable difference between males and females who have mental illness, although mental illness is slightly more prevalent among women than men (KNPD, 2011). In fact, according to the European Health Interview Survey carried out in Malta, women have a high rate of experiencing chronic depression when compared to men, that is, 7.7% and 5.4% respectively (Health Interview Survey, 2008). In addition to this, it was concluded that women have a higher expectancy of chronic anxiety than men (12.2% and 9.7% respectively).

In the World Report on Disability, it is stated that more than 1 billion people worldwide are recognised to have some form of disability. Statistically it is expected that disability will increase in the coming years. This may be due to an increase in disability in elderly people and an increase in chronic health conditions which includes mental illness (Chan & Zoellick, 2011).

2.3 Mental Illness and Disability

According to the UN Convention on the Rights of Persons with Disabilities (CRPD), people with mental illness should benefit from equal opportunities and treatment as any other disability including laws, policies and other legislations (UN, 2006), therefore mental illness is considered as a disability. This is also clearly noted in Article 1 of the same convention where it states that “[p]ersons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (p. 4).

According to the British Equality Act, a person has a disability if s/he has either a physical or a mental illness with the impairment having a long-term effect on the person. The Equality Act states that mental illnesses such as anxiety, bipolar disorders, schizophrenia, personality
disorders and several others, give rise to disability (Equality Act, 2010). According to the World Health Organisation (WHO), mental illness is one of the leading causes of disability, in fact, it is a major reason for granting the person with a disability pension (WHO, 2000).

The Equal Opportunities (Persons with Disability) Act (2000), in Malta, also supports the statement above (Laws of Malta, 2000). It also states that the term ‘mental disorder’ should have the exact meaning as described in the Mental Health Act which is that “a mental disorder is a significant mental or behavioural dysfunction, exhibited by signs and, or symptoms indicating a disruption of mental functioning” (p. 3). The Mental Health Act that came into force in Malta in 2014, focuses on the regulation of mental health services, care and rehabilitation for people with mental illness. It aims to promote and uphold the rights of these persons which includes access to all political, economic, civil, social, religious and educational rights without any discrimination (Laws of Malta, 2012). In addition to this, it focuses on the quality and the standard of treatment, which should be received holistically as any other individual.

When considering the social model of disability, people with mental illness are disabled by society as they too encounter several social barriers, even though the impairment is not always immediately obvious (Equality Act, 2010). This is another implication that mental illness is in fact a disability.

2.4 Mental Illness, Stigma and Discrimination towards People with Mental Illness

As discussed in the last paragraph of section 2.3, the social model of disability says that disability is caused by society and the barriers that it imposes on the person, rather than by the person’s impairment. People with mental illness encounter several disabling barriers, with one of the most significant and dominant factor being stigma. Stigma is a word that comes from the Greek word stigmata which evokes shame and discredit on a person. It is constructed by negative feelings, behaviours and attitudes towards an individual, in this case the person with mental illness (Overton & Medina, 2008). As Goffman (1963) discussed, people who are stigmatised form what is called a ‘virtual social identity’ where they are seen as outcasts in society. Wahl and Harman (1989) identified two types of stigma: the perceived and the experienced. Perceived stigma involves negative attitudes and attributes by the general public in society which causes a person to devalue another person (Gluck, 2015). Experienced stigma
is stigma that is actually experienced by both people with mental illness and their families which leaves an impact in their lives (Cechnicki, Angermeyer, Bielanska, 2011). As Batastini et al., (2014) stated, “stigma refers to the negative effects from a label placed on a group of individuals” (p. 524). People with mental illness face stigma from their peers, school personnel or co-workers and other people who are involved in their social network (Pinto-Foltz, Logsdon & Myers, 2011). Apart from being stigmatised by their peer groups, persons with mental illness can also experience stigma from health care professionals and the general health and psychiatric sector, according to the Mental Health Commission in Canada (Pellegrini, 2014). This stigma in turn leads to barriers such as a decrease in the quality of care together with treatment and recovery care (Pellegrini, 2014). Stigma results in poor quality of care as it promotes negative attitudes and stereotypes about people with mental illness, insufficient care by health-care providers, discrimination and unfair treatment (Knaak, Patten & Ungar, 2015). These all lead to negative impacts on the physical, psychological and social relationship of the person with mental illness (Yen, et al., 2009). The most common feelings that people with mental illness experience include, humiliation, patronisation and the feeling of being punished. Pellegrini also discussed that discrimination can lead to poor treatment strategies which in turn leads to a decreased chance of recovery and when it comes to the medical setting, the health professional may refuse to treat psychiatric symptoms (Pelligrini, 2014).

People with mental illness are usually labelled and stigmatised because of their appearance, behaviour and their socio-economic status. In addition to this, the media might depict mental illness in a negative manner which exacerbates the situation (Corrigan & Watson, 2002). An example of the latter is the news about the plane crash tragedy in the Alps, in March 2015. This added further stigma on people suffering from mental illness, as was reported by the Richmond Foundation in the Malta Independent (2015). People with mental illness might be discouraged to seek help early on in their lives due to fear and discrimination towards them. The impact of the media on people with mental illness will be further discussed in section 2.6.

Throughout history, people with mental illness have been portrayed negatively in society (Mondimore, 1999). At present, they are still considered as being lazy, dangerous and violent (Gonzalez-Torres et al., 2006). Their families blame ignorance and again the media for this. For instance, schizophrenia is associated negatively in media coverage and in public representations. This issue again, is further discussed in section 2.6. In their study in 2006, Gonzalez-Torres et al., came up with seven categories of stigma and discrimination, through a
qualitative study which included focus groups. The seven categories that were brought up included, “Mental illness vs. Lack of will, Prejudice related to dangerousness, Over-protection-infantilisation, Daily social discrimination, Discrimination in health care, Descendants, Avoidance-social isolation” (p. 14). An overview about these seven categories will be discussed in the following paragraph.

To begin with, the first category deals with mental illness vs lack of willpower. The stigma that was experienced by people with mental illness in this study was due to lack of understanding about the illness and lack of willpower. They were perceived as being lazy and overdramatic. Apart from the latter two, people with mental illness were seen as being dangerous, unpredictable and/or psychopaths (Gonzalez-Torres et al., 2006). This gives rise to the second category which is prejudice related to dangerousness. Again, the media is blamed for these prejudices as according to them it offers false images about people with mental illness. The third category is over-protection-infantilisation. This involves the relationship between people with mental illness and their carers which is described by them as being very intense, and the feeling that they are being overprotected. This eventually restricts their “individuality and their opportunities for personal growth, beyond limitations of the illness itself” (p. 18). Gonzalez-Torres et al., described daily social discrimination as their fifth category. Here they discussed how people with mental illness are perceived differently when other people are aware that they have a mental condition including at work or when carrying out daily errands. Apart from being discriminated in these aspects of society, people with mental illness are also discriminated in the health care. In fact, people with mental illness were not taken seriously and were underestimated when they showed some form of symptoms, and blamed everything on their mental condition. The sixth category is descendants. It is believed that a mental illness is inherited from one generation to the other. For example, the risk of schizophrenia is approximately 11 times higher in people who have a relative who already suffers from it. This affected a person with mental illness when it came to the possibility of having children, as they were mistreated. In addition to this, idea of having children was opposed by their family members and also by health care professionals (Gonzalez-Torres et al., 2006). The final category that was discussed in Gonzalez-Torres et al. study was avoidance and social isolation. Due to negative portrayals and discrimination, people with mental illness tend to isolate themselves from friends and stop going to work leading to social isolation.
As Gostin, 2008 stated, "[t]he maltreatment of this vulnerable population has been reinforced by the hurtful stereotypes of incompetency and dangerousness" (p. 906). As a result, people with mental illness tend to live in isolation in order to try and protect themselves as they also feel that their families are over-protecting them, as stated in the previous paragraph (Gonzalez-Torres et al., 2006). However, the reason for this response might be because family members feel they are being discriminated against, as well (Gonzalez-Torres, et al., 2006). This issue is taken up later on in section 2.14.

People with mental illness are also constantly labelled as being unpredictable and 'psychopaths'. In fact, it is noted by these individuals that they are treated differently by other people when the latter learn that they have a mental health problem (Gonzalez-Torres et al., 2006). Due to stigma that is imposed on them, people with mental illness are also faced with lack of access of services and support, poverty and homelessness and unemployment (Borg et al., 2011). The study by Schulze & Angermeyer (2003) used focus groups to research the subjective experiences of stigma. From this study, it was concluded that there was a “reduction of social contacts” (p. 303) in people with schizophrenia, showing further the negative impact of stigma.

As clearly seen in the previous two paragraphs, people with mental illness may isolate themselves from friends and even stop going to work (Gonzalez-Torres et al., 2006) because of the way other people perceive and stigmatise them. In fact, people with mental illness might experience breakdown in relationships either with their partners, families and/or friends. This may eventually lead to social isolation (Parle, 2012). As Corrigan (2004) stated, “[i]t diminishes self-esteem and robs people of social opportunities” (p. 614). In Borg et al.’s, (2011) study, the participants reported that they had a long history of crisis events with their family members, which was either gradual or instant. They also explained how these crises affected their daily quality of life claiming that they lost the skills and structures of everyday life. Lastly, they also mentioned several complexities they encountered within the family involving stressful situations and strenuous emotional circumstances (Borg et al., 2011).

In his book ‘Stigma: Notes on the Management of Spoiled Identity’ (1963), Erving Goffman wrote about the idea of stigma. As stated in the first paragraph of this section, stigma comes from the Greeks and refers to it as the “bodily signs designed to expose something unusual and bad about the moral status of the signifier” (p. 1). He identified three types of stigma, including
stigma of character traits, stigma of group identity and physical stigma (Crossman, 2016). To begin with, stigma of character traits involves stigmatising individuals due to their character, behaviour and beliefs. Stigma of group identity is stigma towards people who come from a particular race or religion, and lastly physical stigma, is stigma towards people who have some form of physical disability (Crossman, 2016). People with mental illness are mostly faced with stigma of character traits, as they are associated with several negative stereotypes, as will be discussed in section 2.5. As Kleinman & Hall-Clifford (2009) discussed, Goffman “viewed stigma as a process based on the social construction of identity” (p. 418).

2.5 Mental Illness, Labelling and Stereotypes in People with Mental Illness

People with mental illness have long been labelled and stereotyped negatively in society as previously discussed. Negative images portray negative thoughts about these people which further promotes discrimination. For instance, people with schizophrenia are viewed in society as being violent and dangerous (Angermeyer et al., 2003). Again, this is all exacerbated by the media which tends to show people with mental illness as being murderers, rapists and homicides, as seen later in this chapter. Furthermore, as mentioned by Edney (2004), a person with mental illness is also depicted as being a “rebellious free spirit; violent seductress; narcissistic parasite; mad scientist; sly manipulator; helpless and depressed female; and comedic relief” (p. 3).

Angermeyer & Matschinger (2003) discussed two opposing views on labelling. Firstly, as seen from a clinical point of view, labelling provides a form of orientation to the person with mental illness and his/her family as they will get a better understanding about the condition, since “[t]he uncertainty and false beliefs will be replaced by a better understanding of the nature of the problem” (p. 304). In addition to this, if the mental problem is considered to be an illness, the person will be granted privileges like any other person with disability. However, in a study by Farina (1998), it showed that the effects of labelling contradict these ideas as it insists that labelling produces negative stereotypes about people with mental illness, which will in turn lead to further discrimination against them (Angermeyer & Matschinger, 2003). In fact, in this same study by Farina (1998), it was concluded that labelling a person with mental illness as having mental health problems exacerbates stigma rather than reducing it. It was also concluded that people with mental illness are perceived as being dangerous, and produces fear and social distance.
2.6 Mental Illness and the Media

Over the past years, many studies including Francis et al. (2001), have illustrated the negative effects of the media on people with mental illness. It is an important aspect that influences the public’s perception and how people with mental illness are viewed in society (Edney, 2004), especially the connection with violence. News reports such as the 2012 mass shooting in the Aurora cinema and past murders in Malta all blame mental illness and continue to prompt concerns and increase the stigma on people with mental illness.

As already discussed, it is mostly negative stories about people with mental illness that hit the news headlines, as seen previously in the worldwide coverage about the story of the Germanwings plane crash, including in the Malta Independent newspaper. In the British newspaper ‘The Sun’ it referred to this incident as ‘Madman in the Cockpit’ (2015). The latter further increases the stigma that people with mental illness are a burden in society and are incapable of contributing in a positive manner in their community (Edney, 2004). In addition to this, it also emphasised that they are danger to themselves and to others. Edney (2004) stated that in television characters, people with mental illness are portrayed as being crazy and drug abusers. Movies such as ‘One flew over the Cuckoo’s nest’, ‘Girl interrupted’ and ‘Shutter island’ all depict the typical stereotypes of people with mental illness such as being ‘troublesome’, ‘mad’ and ‘confused’ people (Edney, 2004). In addition to this, they often have a role where they are portrayed as poor and homeless people and are always chased by the police. In fact, as Olstead (2002) stated people with mental illness are “lacking in markers of social identity” as they are being portrayed negatively in society (p. 625). Furthermore, according to the Mind report in the UK, media coverage about people with mental illness leads to a negative impact on their lives, including negative effects on their own mental health, the feeling that they are in isolation and an increase in suicidal thoughts. People with mental illness feel ashamed and embarrassed when viewing such negative media coverage (as cited in Edney, 2004). The study by Schulze & Angermeyer (2003) showed that the representation of mental illness in the media is discriminating and hurtful which exacerbates the stigmatisation experience.

To conclude on a positive note about mass media, a website entitled ‘StigmaBusters’ developed by NAMI, aims to increase the positive depictions of people with mental illness by discussing their personal struggles and ways how they combat the illness (Edney, 2004). Another positive
portrayal shown in the media was in the 1997 film ‘As Good as it Gets’, where a man with obsessive compulsive disorder was able to overcome barriers in society, and with help of therapy and medication, he achieved his dreams and learnt how to live and how to control his illness (Edney, 2004). As seen in this section, there are positive and negative implications on how the media portrays people with mental illness. It is not always depicting the person with mental illness negatively, but it can be used to promote positive attitudes and if used properly might also minimise the stigma that is present in society. (Edney, 2004).

2.7 Mental Illness and Employment

As any other person in society, employment gives a sense of well-being and responsibility even in people with mental illness. Advantages of employment include an income and financial stability, providing an increase in responsibility and eventually giving a sense of importance and achievement to the individual with mental illness (Batastini, Bolanos & Morgan, 2014). In addition to this, WHO identified five other categories how work benefits people with mental illness. These include social identity, time structure, regular activity, collective effort and purpose and lastly social contact (WHO, 2000).

Despite these benefits, people with mental illness may find it difficult to find employment or are under-employed. According to the WHO (2000), mental illness affects both the functional and the working capacity in several ways. As found in Kumar & Frangou (2010), 50% of people who have bi-polar disorder were working below their qualification standards or were working as volunteers or part-timers. In this longitudinal study of 261 people who have bipolar disorder in the US, it was also concluded that 40% of people with this particular condition had a limited annual income even though they had good educational background and high college degrees (Kumar & Frangou, 2010). People with mental illness may have different trades and professions such as teachers, plumbers, lawyers, and this shows that having a mental illness does not make a person unfit or incapable to work (Malta Independent, 2015).

The difficulties faced by people with mental illness to find an adequate job may be partly due to attitudes of stigma and discrimination by employers. These stigmatising attitudes are exacerbated in offenders with a mental illness as they are portrayed by society and again by the media, as having both psychiatric and being offenders also implies that they have criminogenic needs. These stigmatising attitudes therefore impede the person from accessing employment.
(Batistini, Bolanos & Morgan, 2014). Through their focus groups, Angermeyer, Schulze & Dietrich (2003) pointed out the difficulty in reintegration at work, when a person with mental illness undergoes psychiatric treatment due to negative comments and discrimination.

Large-scale studies have shown that the rate of unemployment of people who have a mental illness is approximately three to five times higher when compared to non-disabled people in the US (Stuart, 2006). In Malta, 2.4% of people with mental illness are unemployed (KNPD, 2011). 21.2% of people with mental illness has elementary work as their occupation. Service and sales workers and clerical support workers are also quite common adding up to 18.1% and 14.1% respectively (KNPD, 2011). Employers are reluctant to employ someone with mental illness or a past psychiatric problem. In fact, they are more likely to hire someone who has a physical impairment rather than someone who has a mental illness (Stuart, 2006). Again here, stigma plays a very important role, as it leads to these employment barriers (Stuart, 2006). However, according to the 2011 Census, in Malta, 88.6% of people with mental illness, claimed that they were actually ready to start working.

2.8 Mental Illness and Institutions

As already mentioned in section 2.5, people with mental illness were considered shameful in past times, in fact families used to set them aside from society and were eventually then admitted to institutions, where it may have resulted in passivity meaning, becoming dependent on others (Gostin, 2008). Non-governmental organisations (NGOs) constantly discover horrifying conditions in institutions or residential homes for people with mental illness (Gostin, 2008). This is also supported by Erving Goffman in his book ‘Asylums: Essays on the Social Situation of Mental Patients and Other Inmates’ (Goffman, 1961). It is also interesting to note that conditions do not seem to have improved considerably since Goffman wrote about institutions in the early 60s. The shocking discoveries in the UK, include isolation, small confined filthy spaces, lack of medical treatment and care, mal-nutrition, physical abuse and lack of clothing (Gostin, 2008). Institutions might have negative results on the health and development of these individuals with mental illness and also on their life chances (WHO, 2010). As Gostin (2008) stated, "[t]he right to a 'private and family life' under the European Convention can be a powerful tool to safeguard the civil rights of persons with mental illness” (p. 910).
In the same study, Gostin (2008) identified four main correlated human rights that people with mental illness lack the enjoyment of. These were liberty, dignity, equality and entitlement and access to services. Culture plays an important role in the acceptance of people with mental illness and how these people are treated and included in society (Gostin, 2008). During his investigation whilst carrying out the study, Gostin noted the difference between Japan and India. In Japan, mental hospitals had extensive and restricted conditions, so extreme that a person lost the use of his legs due to isolation for 30 years. On the other hand, the institutions in India had more hospitable conditions. A reason for this could be that in India’s culture, people with mental illness were cared for within their families and communities and were more accepted in society unlike Japan where mental illness was portrayed as a matter of shame (Gostin, 2008).

In the 1960s, civil rights advocates fought to close mental institutions as they were considered unacceptable places where people with mental illness were treated poorly and where isolation, abuse and neglect were promoted (Gostin, 2008). These advocates insisted that these people have the same rights as any non-disabled person and should be included in society. However, in his article, Gostin actually concluded that “[w]hat eventually transpired was a massive transmigration of mentally ill persons from ‘old’ to ‘new’ institutions, such as jails, remand centres, prisons, nursing homes and homeless shelters” (p. 910). Instead of providing a future of compassion, care and inclusion, people with mental illness had and are still being faced with bullying and maltreatment. Gostin (2008) suggested that mental illness should be seen as a human rights imperative rather than just a social problem in order to adopt the above four interrelated human rights.

2.8.1 Mount Carmel Hospital

In Malta, the main state institution for people with mental illness is Mount Carmel Hospital and is situated in Attard. It was not always called Mount Carmel, in fact it was recently that it adopted this name. Historically, as already stated in this chapter, people with mental illness were regarded as being possessed, even in Malta and were eventually admitted to the Order of St. John’s Sacra Infermeria which was located in Valletta. People with mental illness were housed in small chambers and confined to bed. Those people who had severe mental illness were transferred to the basement where they were chained to the room’s wall (Bugeja Coster, 2008). During this era, people with mental illness were beaten up and treated in horrible ways.
by being confined to dark rooms and given cold baths. Those people who were deemed incurable were transferred to Casa Di Carita, also known as Ospizio, located in Floriana. Eventually, a hospital was set up in an old mansion in Floriana and was called Villa Franconi. This mansion was the residence of a Knight of the Order of St. John, Bali Fra Fabrizio Franconi, and following the conversion to a mental hospital, it adopted the name of Ta’ Frankuni, hence the traditional remark given to the mental institution (Savona-Ventura, 2004). Floriana, being a small and curious neighbourhood was not the ideal place to have a mental institution as residents often teased and provoked the patients. Therefore, inmates were transferred to Mount Carmel Hospital in Attard where it was more isolated from houses at the time. Even though having the name of Mount Carmel Hospital, it is still called Ta’ Frankuni at times, even nowadays and still imposes negative beliefs about the hospital (Savona-Ventura, 2004).

Mount Carmel Hospital was completed in 1861 and primarily called the ‘Lunatic Asylum’. The first two hundred and fifty-three patients were transferred during the night in July 1861 from Villa Franconi and the main aim at the time was to keep people with mental illness away from society (Savona-Ventura, 2004).

2.9 Mental Illness and Suicide

It is evident that there is a link between mental illness and suicide, being it attempted or thought (Nock, Hwang, Sampson & Kessler, 2010). According to the Mental Illness Fellowship in Victoria, there is a ten per cent risk of suicide in people with mental illness. Furthermore, NAMI (2016) stated that approximately 90% of individuals who commit suicide experience mental illness at some stage in their life. Depression, schizophrenia, bipolar and personality disorders have all been linked to suicide and/or suicide attempt. Unemployment, family problems, isolation and loss of a spouse may all contribute to a higher risk of suicide (Mental Illness Fellowship Victoria, 2013). According to the National Alliance on Mental Illness, suicide is the 10th leading cause of death in adults in the United states whilst it is the 3rd cause of death in adolescents between 10 till 24 years of age (NAMI, 2016).

2.10 The Impact on the Family

Having a relative with mental illness leaves an impact on all family members. In fact, there have been several studies about the impact, being either positive or negative, and/or challenges
of having a family member with mental illness. It has been reported that looking after a person with mental illness affects the caregiver/s’ emotional state and life in general (as cited in Fadden, Babbington & Kuipers, 1987). These impacts and/or challenges can be found in different areas including general health (physical and mental), social relationships and work (Goossens, et al., 2008). In addition to this, studies have shown the importance of treatment and care towards family members who have a relative with mental illness (Judd et al., 2002), in order to provide or improve intervention strategies that help the disabled person and his/her family (Shibre et al., 2003), such as in leisure activities, family relation, employment and finance. Approximately 90% of people with mental illness receive their support from family caregivers (Ostman, Hansson & Andersson, 2000). Ogilvie et al., (2005) described a caregiver as “the usually unpaid non-professional, such as family and friends, who has a significant input to the care and support of those affected by severe psychiatric illnesses” (p. 26). However, many health care professionals claim that families of a person with mental illness are often over-protective and interfere in their daily life (Rethink, 2003). Many also say that they are unaware of what mental illness really is and what treatment is provided to people with mental illness (Riebschleger, 2001). When the family has one of its members with a mental illness, their life undergoes numerous changes such as distress and a sense of burden and in fact, their own life and health is altered as well (Jonsson, et al., 2011). Stereotypes, as already mentioned in section 2.5, about the families are also very much present in society. Negative stereotypes include that they are incompetent and dysfunctional in society. However, on a positive note, they can also be brave when caring for their family member with the illness (Banks, 2003).

2.11 Adaptation in the Family

When having a family member with mental illness, the family (parents, partner, child and/or siblings), have to adapt to the changes that might occur. In the beginning, this might lead the family to isolation as they feel that they are on their own and have difficulty to understand and/or maintain normality. This sense of loneliness experienced by the family, came about as a result of the emotions that were elicited by the consequences of the mental illness (Jonsson, et al., 2011). The family often see mental illness from a medical point of view as they are constantly searching for a cure for their relative as they associate mental illness with a brain disease. (Jones, 2002). While in the process of adapting and changing the lifestyle, the family is trying to make sense and is trying to understand the illness and eventually coping with it.
(Jonsson, et al., 2011). Evidence of this is quoted by a relative of a person with mental illness in Jonsson et al’s qualitative study, where she stated that,

> every day, different things happen with my father, and then you automatically get used to all these things that can happen, how he answers the phone, what he’s like when he comes over, and all these things eventually become a part of your everyday life … I do not find anything complicated, because it is my everyday life. You just live with it; it’s that simple because it’s my dad. (daughter, 23 years old, 2011, from Jonsson, et al.) (p. 32).

When facing a change alone, the family member might become unpredictable and aggressive towards the person with mental illness as the latter may act differently when being with other people than when s/he is with them and might therefore cause frustration in the family member caring for his/her relative with mental illness. According to a statement by a partner of a person with bipolar disorder,

> you become a little isolated more or less; you see, you have carried it around by yourself a lot, because with this type of illness, she can live totally normally among other people and no one notices anything, other than those closest to her. (p. 32) (Jonsson, et al., 2011).

### 2.12 The Impact of Stress on the Family

Furthermore, family members might suffer from stress when having to care for one of their members with mental illness especially in the case of families with depressed parents (Du Rocher Schudlich et al., 2008). This may lead to physical, financial and emotional pressure within the family (Shankar, & Muthuswamy, 2007) together with negative impacts on family and social relations and on work capacity, since caring for a member with mental illness might take up a lot of his/her time (as cited in Jonsson, et al., 2011).

#### 2.13 Female Family Members

An interesting study by Gonzalez-Torres et al (2007) noted that female members of the family were the ones who are mostly responsible for the person with mental illness, specifically mothers. This is a common stereotype of the female gender as they are portrayed as taking the responsibility for the care of their children and staying at home (Gonzalez-Torres et al., 2007). Similarly, in the research by Shibre et al., (2013), it was noted that most of the financial
difficulties were associated with the female family members, the widowed and the separated/divorced as men are associated with being the bread-winners of the family whilst the female member adopts the caring role. It is also shown that relatives that suffer the most socially and in the working environment are mothers, spouses and daughters of people with mental illness which could be again due to this caring role of female family members (Shibre et al., 2013). Furthermore, in Malta, a study carried out by Fenech & Scerri (2014) showed the sense of guilt that is especially experienced by mothers of people with mental illness as they “grieved at lost expectations they held for their ill son or daughter” (p. 20).

2.14 Stigma and Discrimination towards Family Members

Family members experience discrimination towards them which might be due to existing prejudice towards people with mental illness in society including the media as described in section 2.6. In addition to this, they face discrimination by their friends as the latter do not tolerate the implications and the sacrifices that family members have to make when caring for a person with mental illness, leading to isolation (Gonzalez-Torres et al., 2007). A Moroccan study by Kadri et al., (2004), showed that apart from the person with mental illness, their family also suffers from stigma. They discovered that stigma is evident because of the illness itself and the poor quality of life. From the sociodemographic data of this study, family members reported that they felt they are harmed and maltreated and that they are being neglected in society especially from their neighbours and friends. The two types of stigma that were mentioned earlier in section 2.4, are also felt by family members. From Angermeyer et al.’s (2003) study, it was concluded that stigma actually has a significant impact on family members who have one of their relatives with mental illness, whereas a small proportion of the participants in the study also identified personal stigma experience such as disruption in relationships with other family members and damaging their self-esteem.

In their study, Angermeyer et al (2003) also concluded that the family’s primary encounter with stigma is when they meet the professionals. They feel stigmatised because of the lack of interest and lack of appreciation towards their relative with mental illness. In addition to this, they feel that the professionals also impose a sense of stigma towards people with mental illness (Angermeyer et al., 2003). As one relative in this same study stated, “[r]elatives are pushed to the back seat and are not considered ‘part of the team’” (p. 595).
2.15 Burdens on the Family

The study by Kumar & Saini (2012) described several major burdens on the family when one of its members has a mental illness. These are the financial burden; the disruption of family routine activities and family leisure; the interaction between the person with the mental illness and other family members; and lastly the effect on the physical and mental health to others (Kumar & Saini, 2012). These authors also noted that due to the lack of employment of people with mental illness, the financial barrier is the most frequent burden on the family.

According to a cross-sectional study in rural Ethiopia, financial issues might also arise because of treatment costs, whether for medications, admissions to hospitals or visits to health professionals (Shibre et al., 2003). Financial problems might in turn lead to stressful situations within the family (Du Rocher Schudlich, Youngstrom, Calabrese & Findling, 2008). In addition to this, they might even increase the risk for further socioeconomic barriers (Chan, 2011) which might eventually lead the family to develop psychiatric conditions themselves (Beevers, Wells & Miller, 2007).

As stated in section 2.11, when having a family member with mental illness, there could be disruption of daily routine activities within the family, due to his/her behaviour. As mentioned, it takes quite some time for the family members to adapt and to try to cope with the situation and maintain normality. This time is taken from the family's leisure, holidays and recreation activities (Kumar & Saini, 2012). It might also limit the family member who is the primary caregiver from going to work as s/he has to look after the person with mental illness and would not be able to leave him/her alone at home (Wankiiri, Drake & Meyer, 2013). This could eventually lead to disturbance in the interaction between the family members. Caring for a person with mental illness, becomes the sole responsibility and duty for the family member. An illustration of this can be seen from a sister of a person with mental illness in Wankiiri et al’s, (2013) study, where she stated, “[i]t is me and only me who looks after my brother… there are other family members in the home but they never want to stay around with him…”, (p. 59).

However, on a positive note, the caregivers of the person with mental illness constantly tries to adopt a positive cognitive coping strategy in order to deal with the situation, including education, advise and motivation to the caregivers (Kumar & Saini, 2012).
2.16 Impact on the Quality of Life of the Family Members

Lastly, there is also an impact on the quality of life of persons taking care of people with mental illness (Jonsson, Skarsater, Wijk & Danielson, 2011). It is a trying and challenging experience when one has to care for a family member who has a mental illness. Providing constant care and support is essential to people with mental illness. However, caring for them is surely not an easy task, as families find themselves burdened by the situation as they may feel that they have no life of their own (Jonsson, Skarsater, Wijk & Danielson, 2011). The qualitative study by Jonsson et al. was carried out using interviews and used an interpretative approach to get a deeper understanding of the families’ experiences. The sense of loneliness and responsibility was also noted in the study by Voort et al., (2007) in the Netherlands. As cited in this study, reports showed that providing care to a member of the family with mental illness may cause burden, anxiety, poor quality of life, poor social, emotional and physical functioning and poor health (as cited in Voort et al., 2007). In addition to this, if these family members are rejected by society and their consequences of how they have to adapt and adjust their lifestyle are not believed, may lead to further avoidance of social contact and will refrain sharing their thoughts (Jonsson, Skarsater, Wijk, & Danielson, 2011). Panigrahi et al., (2014) stated that, “[q]uality of life in caregivers is inversely related to their burden” (p. 58). In fact, in another study by Caqueo-Urizar et al., (2009), it was reported that the poor quality of life of the caregivers was associated with the burden of the illness.

2.17 The Impact on the Family in Malta

In Malta, a study carried out by Fenech & Scerri (2014), also showed similar impacts on Maltese families who has a relative with mental illness. Using an Interpretative Phenomenological Analysis (IPA), four themes were identified from their research including the “range of emotions, increased responsibility, toll on physical health and change in lifestyle” (p. 19), together with a number of negative physical and emotional responses. It is interesting to note that these themes all correlate with the above findings from international research, as discussed in the previous sections. When considering the range of emotions, caregivers feel sadness, worry, guilt, frustration and burnout when caring for their family member. The sense of responsibility is also an important issue that is emphasised and parents are constantly worrying who will look after their son/daughter without their assistance (Fenech & Scerri, 2014).
Similarly to the study by Jonsson et al., in 2011, the Maltese participants in Fenech & Scerri study all stated that there was a drastic change in their lifestyle which could be due to social restrictions and stress. This could eventually lead to changes in the physical health of the family member who is caring for their relative with mental illness, due to the constant strain and the dependency of the person with mental illness on the caregiver. From this study, it was evident that having a relative with mental illness has an impact even on Maltese families. The effects of stigma are also mentioned in this Maltese context study. Participants claimed that because of the stigma that is present, it mimics full participation in society which ultimately could lead to social exclusion (Fenech & Scerri, 2014). As mentioned in the above studies, stigma leads to unemployment. This is also the case in Malta where reduction of job opportunities was the main factor which caused financial stress on family members even though it was not necessary that the person with mental illness lived in the same household (Fenech & Scerri, 2014).

2.18 Mental Health Support in Malta

In Malta there are three main non-governmental organisations that support people with mental illness and their families. One of these is the Richmond Foundation, a non-governmental and voluntary organisation that was founded in 1993. It is run by ten Board of Trustees members with one member who is either a mental health service user or a relative of a person with mental illness (Richmond Foundation, 2015). The Richmond Foundation aims to aid the person to find community-based rehabilitation facilities and deals with providing housing with support. In addition to this, it provides opportunities for employment, training, minimise the barriers that they might face in the community to live life as independent and as full as possible. Furthermore, the organisation works in the promotion of positive public awareness about mental illness and provides good mental health within the general population (Richmond Foundation, 2015).

The Mental Health Association Malta (MHA), is a voluntary association in Malta that was set up in 1982 by Professor Abram Galea, a psychiatrist, a few members of Mount Carmel Hospital and some other individuals including relatives of people with mental illness (MHA, 2015). MHA is led by relatives of people with mental illness and with Mr. Andrew Scicluna currently being president of the organisation. Its main aim is to support people who have a mental illness and improve their quality of life together with that of their families. In addition to this, MHA aids in educating the person with mental illness and their families about the condition, together
with providing coping techniques to all individuals. (MHA, 2015). The association also promotes awareness about mental illness in an attempt to decrease the stigma and other barriers that both people with mental illness and their families face in society.

Finally the St. Jeanne Antide Foundation (SJAF), is a family and community based NGO which provides constant support in a holistic manner to people with mental illness and their families taking into account the mental and social factors. It works hand in hand with state entities and other NGOs having the same scope. It was founded by the Malta Province of the Sisters of Charity of St. Jeanne Antide together with other volunteers. It is managed by a Governing Board with a Chief Executive Officer. The Foundation is run by a community of Sisters and volunteers to support and empower these people who are still being excluded in society. Their mission is to provide them with moral and spiritual support (St. Jeanne Antide Foundation, 2016). It also aims to support and provide empowerment to people whom are excluded in society. Furthermore, it aims to target the families’ crises and difficulties when caring for their relative with mental illness, address financial problems and unemployment, organise family consultancies and support groups to council them on how to help their family member, and lastly it promotes education for vulnerable people (St. Jeanne Antide Foundation, 2016).

Apart from these three NGOs, there is Mount Carmel Hospital (MCH), mentioned in section 2.8.1, which is the state mental health hospital, offering both in-patient and out-patient services and Chambray Mental Hospital which is found in Gozo. Apart from these two hospitals, the state also offers mental health day centre services in different localities including Qormi, Paola, Bormla, Żejtun and Floriana. In addition to this, there are primary and secondary mental health clinics. Other community services include the crisis intervention team operating at Mater Dei hospital (MDH), hostels and community homes, the community outreach team, the psychiatric outpatient department at MDH and roaming clinics which are still yet to be established (GOV, 2015).

2.19 Conclusion

Both people with mental illness and their families face several challenges and barriers in society, especially through stigma and discrimination. Evidence of these barriers can be seen in several aspects of their daily life including in the health and care of both people with mental illness and their families (Gonzalez-Torres et al., 2006). As a result, people with mental illness
may lead themselves into isolation which could be an excuse for them to avoid the social rejection that is imposed on them. Gonzalez-Torres et al. (2006) discussed that relatives of people with mental illness also face discriminatory situations which “sometimes contribute to such experiences through an over-protective attitude, which may foster the patient’s dependency” (p. 22). Education should be imposed on the general public in an attempt to minimise the burdens that these individuals are faced with. In addition to this, mental health services should be incorporated in order to provide support and educate family members about mental illness and how to deal with barriers that it brings with it (Shibre, et al., 2003).
Chapter 3
Methodology
CHAPTER 3: METHODOLOGY

3.1 Methodology

This chapter focuses on the research plan including the methodological choices made for the study. It includes a detailed explanation of the design of the research, the theoretical framework utilised, the sampling used, and relevant ethical issues that are taken into consideration.

3.2 Research Design

A qualitative approach was used in this research study. This type of approach provides in-depth knowledge about the experiences of people with mental illness, including their families, in society. It aids in understanding the research participant in his/her social life and how society treats him/her (Brikci & Green, 2007). In addition to this, it also provides subjective understanding about the impact, whether positive or negative, on the family having one of its member with mental illness. As Denzin & Lincoln (2005) clearly stated, "[q]ualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them" (p. 3). It therefore offers a great potential especially since research about this sensitive topic is limited (Smith, 2010).

3.3 Methodological Frameworks

The main theoretical framework of this study, as already mentioned in Chapter 1, is the social model of disability. When trying to understand definitions of disability from a social lens, several issues come to mind including inequality, labelling, oppression, stigma and discrimination. As clearly described by Mike Oliver, it is not the impairment or the limitation of the individual that causes a problem. It is in fact society that creates barriers and that makes the person disabled, as it lacks the appropriate services, facilities and accessibility for these people (Oliver, 1990). As clearly described in the literature review in Chapter 2, people with mental illness also encounter several barriers in society which limit the ability of the disabled person to function ‘normally’. In fact, the social model of disability has been described as ‘the big idea’ of the British disability movement, as already described in Chapter 1 (Hasler, 1993).
The other conceptual framework used in the study is the phenomenological approach. As stated by Creswell (2007), "phenomenology provides a deep understanding of a phenomenon as experienced by several individuals" (p. 62). Hermeneutics was used to focus on the individuals’ meaning of lived experiences (Creswell, 2007).

For Edmund Husserl, phenomenology entails the careful examination of human lived experience. Husserl insisted that we should ‘go back to the things themselves’, with the ‘thing’ referring to the content of consciousness. Husserl’s idea of phenomenology involves stepping out of our ‘natural attitude’, that is, getting out of our everyday experience. In fact, he insisted on adopting a ‘phenomenological attitude’ which involves a reflexive move from where we turn our gaze from. (Smith, Flowers & Larkin, 2009).

As discussed in Chapter 1, Martin Heidegger developed the idea of phenomenology even further. Again, as already mentioned in chapter 1, he speaks about Dasein, his preferred term for the ‘human being’ as it refers to ‘being-in-the-world’. In his book, ‘Being and Time’, Heidegger discussed the relation between Dasein and the lifeworld (the everyday life that we lead) together with the concept of ‘intersubjectivity’, (cited Smith, Flowers & Larkin, 2009). Heidegger also discussed the concept of Mitsein, being-with, as he does not ignore the experience of the ‘other’ (Moran, 2000). In this study, Mitsein referred to the family members who look after their relative with mental illness.

These concepts were used in the research study to explore the lived experience of people with mental illness and of their families. In addition to this, the ‘being-in-the-world’, will be related to the life-world of people with mental illness and to their family by focusing on their shared and overlapping experiences as well as those aspects of their experiences which differ. This can all be related to intersubjectivity because by exploring these experiences, a common ground in the study of human sociology can be found (Duranti, 2010).

3.4 Interpretative Phenomenological Analysis (IPA)

Phenomenology being a theoretical framework, entails the use of Interpretative Phenomenological Analysis (IPA). It is one way of applying the phenomenological approach to research as in this case lived experiences of people with mental illness and their families (Smith, 2008). As Smith & Osborn (2008) stated, IPA “explores in detail how participants are
making sense of their personal and social world, and the main currency for an IPA study is the meanings particular experiences, events, states hold for participants” (p. 53). This methodology enabled the researcher to get a closer look at the participant’s personal life especially when conducting in-depth interviews. The method will be discussed in further detail later on in this chapter.

By using IPA, Smith & Osborn stated that, “[t]he participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world” (p. 53). In other words, this means that IPA aids the researcher to examine the lived experiences and how the lifeworld appears by the individual (Smith, Flowers & Larkin, 2009). IPA draws from three influences: phenomenology as described in the previous section and in the Introduction chapter, hermeneutics and idiography. Heidegger’s philosophy was developed from Husserl’s philosophy where the former was a student of the latter. As cited by Annells (1996), “the term phenomenology expresses a maxim which can be formulated as ‘[t]o the things themselves” (p. 706).

To begin with, “[h]ermeneutics is the theory of interpretation”, (Smith, Flowers & Larkin, 2009, p. 21). Through hermeneutics the researcher tries to discover the meanings, together with the intentions or relations, given to specific phenomena by the individual. In this study, the individuals were persons with mental illness and family members and it was their meanings and experiences that I, as the researcher attempted to interpret. The hermeneutic circle is a very important concept in IPA. As Larkin et al., (2016) discussed, in this ‘hermeneutic circle’ the knower and the known are interconnected and ultimately thrust in the circularity of understanding. The researcher tries to interpret 'the part' and 'the whole' of a context, 'the part' being the interview and 'the whole' being the research study (Smith, Flowers & Larkin, 2009) and the lived experience of individuals in this case, people with mental illness and that of their family members together with the societal perceptions. These perceptions as a ‘whole’ impinge greatly on the lived experience. The ‘part’ therefore refers to the person’s lifeworld and that part of their lived experience they are focusing on through the research. This approach is directly in line with the social model of disability. Hans-Georg Gadamer, whose mentor was Heidegger, described “understanding, prejudice, linguisticity of understanding, historicity, the fusion of horizons and lived experience” (p. 708) as all being significant in the hermeneutic circle (Annells, 1996). In his book *Truth and Method*, Gadamer perfectly described the hermeneutic circle as follows:
Every revision of the fore-projection is capable of projecting before itself a new projection of meaning; rival projects can emerge side by side until it becomes clearer what the unity of meaning is; interpretation begins with fore-conceptions that are replaced by more suitable ones. This constant process of new projection constitutes the movement of understanding and interpretation. (Gadamer, 1975/2004, p. 269).

As previously mentioned in this section, the descriptions that the participant gives, will enable him/herself to make sense of their lived experience. However, IPA also involves double hermeneutic since the researcher is trying to analyse the individual, who is in turn trying to understand what is happening to him/her through his/her experience (Smith, Flowers & Larkin, 2009). Here the active role of the researcher in the process of interpretation, is clearly explained (Roberts, 2013) by trying to interpret the meaning behind the participants’ lived experience.

The third influence on IPA is idiography. This is associated with common themes that arises during the interview which in turn, link things together giving depth to the analysis (Smith, Flower & Larkin, 2009). The analysis must be thorough and systematic and should involve the understanding of how a particular lived experience is understood from the perspective of a particular person in a particular context. Idiography may refer to a single case in its own right or a way of establishing generalisations from that single case (Smith, Flower & Larkin, 2009). IPA “wants to know in detail what the experience for this person is like, what sense this particular person is making of what is happening to them” (p. 3). It focuses on human diversity and variability which is ideal when exploring such a sensitive subject (Eatough & Smith, 2008).

From an ontological point of view, (that is the nature of being), this study was multifaceted. It had more than one perspective, that of the person with mental illness and his/her family members. Each encounter different impacts therefore, having adopted a phenomenological approach there was more than one reality and interpretation. In addition to this, from an epistemological standpoint, IPA adopts an interpretative standpoint (Biggerstaff & Thompson, 2008). As Walsham, 1995 stated, "[i]nterpretive methods of research adopt the position that our knowledge of reality is a social construction by human actors" (pg 376). Therefore, this standpoint helped me combine the lived experiences of the research participants, whether they are people with mental illness and/or their families, so that from their experiences I will try and contribute to knowledge about the lived experience of mental illness.
Given its potential for exploring significant life events and detailed analysis of an individual, IPA was very suitable for studying mental illness. Having a small participant number gives the opportunity to the researcher to have a detailed account on the perceptions and the understandings of the person/s within the social world especially if this account involves cognitive, affective and existential aspects of one’s self (Smith, 2008). In addition to this, it aids the participants to express themselves as much as possible about the lifeworld – Lebenswelt, which as stated in Finlay’s article (2013), is “the matrix of meaning inherent in our ongoing relations with our world” (p. 180). This life world is shared with others through shared language, culture, discourse and history (Finlay, 2013).

3.5 Research Participants

Due to its idiographic commitment, IPA adopts a small sample (Smith, 2008). By using a phenomenological approach, it aided in studying the lived experience of both the participants with mental illness and their family members. The study was carried out in a Maltese context and participants were recruited from Maltese NGOs for people with mental illness. An invitation letter was sent to all NGOs in order to invite their service-users to take part in my study (see Appendix 3A & 3B). Whilst recruiting the participants, I encountered a gatekeeping issue where there was a negative response from a certain professional member of a specific organisation due to the stigma that people with mental illness are difficult to comply with the study. However, this was not the case as there was full cooperation from both people with mental illness and their families to take part in the study. The issue of stigma has already been widely discussed in the previous chapter. Inclusion criteria included four people over eighteen years of age with mental illness and four family members (who were either parents, siblings, partner/spouse and/or child of a parent with mental illness). Interpretative phenomenological approach requires sample homogeneity (Smith, 2008). In this study, the homogenous group was mental illness as this was common among the participants including the family members.

To interview family members who had a relative with mental illness, first I requested the service-users who have a mental illness to choose any one of their family members and then I discussed with the participating organisations to send the invitation letter to these family members (for consent form see Appendix 1A & 1B). This entailed purposeful intensity sampling.
Each participant was given an information letter, either in English or in Maltese according to their preference, about the study. This letter explained what participation entailed of them. In addition to this, the letter also included the contact details of the researcher in case any of the participants wished to ask any questions prior to the interview.

3.6 The Research Method

Semi-structured interviews (see Appendix 4A & 4B and Appendix 5A & 5B) were used in the study in order to provide an in-depth insight on the voice and lived experience of each participant (Seymour, 2001). Participants could choose their preferred language, either Maltese or English. Open-ended questions were used in order for the participants to expand on their lived experience as much as possible and at the same time to decrease any bias letting them speak freely and open up about their lived experience (Hefferon & Gil-Rodriguez, 2011). The questions were formulated in as neutral a way as possible and a certain number of prompts were given. The interview sessions took approximately thirty minutes to forty-five minutes and were recorded using an audio recorder, with the consent of the research participant. Observational points were written on a notebook during the interview.

The interview took place in a quiet setting according to the participants’ preference, either in their home or in any other place where the participants felt comfortable. This was important as the participants disclosed their personal experience, therefore as the researcher, I wanted to make them feel as comfortable as possible in order to obtain a confident and positive communication between me, as the interviewer, and them.

When the interview was finished, the recordings were transcribed. I then distributed the transcripts to the research participants to make sure that their experiences have been represented faithfully and they were given the option to make alterations where necessary, therefore providing them with control over their own stories. Subsequently, I discussed these results with the advisor, who has considerable experience in the area of mental health. This made the study trustworthy and credible. Her insights and feedback inform the analysis presented in Chapter 4.
3.7 Ethical Considerations

Prior to the commencement of the study, approval was sought from the University Research Ethics Committee (UREC). Each participant was informed beforehand about the study and what was expected of them was explained through the invitation sheet (both in English and in Maltese) provided (see Appendices). In addition to this, informed consent (see Appendices) was obtained in writing from each participant. The participants were reminded that they were free to withdraw from the study at any time and that their real names and any identifying personal details will not be used in the study. Moreover, all data was treated with full confidentiality and anonymity. Each individual was advised that an audio recorder will be used during the interview and that as soon as the study is finalised, the recording will be destroyed. The transcripts were validated by the participants prior to analysis and they were allowed to correct and edit any necessary changes in the transcripts.

3.8 Emancipatory Research

Several steps were taken to ensure that the study was conducted on the principles of emancipatory disability research to the maximum extent possible. It followed the six principles of emancipatory research as discussed by Barnes (2001). Emancipatory research should adhere to the social model of disability (Oliver, 1992). In fact, the social model is part of the conceptual framework of my study. Another principle of emancipatory research is accountability. I have made myself as accountable as possible by having an advisor with extensive experience in the area, and by enabling the participants to approve the transcripts. In this study, the participants were given the opportunity to recall their lived experiences through interviews with open-ended questions therefore they were responsible for their own stories. When data is interpreted, it can be interpreted in several different ways and the researcher who is interpreting the data can be influenced by economic, political and cultural factors. This leads to the problem of objectivity. This issue was tackled when I stated clearly the ontological and epistemological standpoint, as discussed in section 3.4 in order to minimise biases and by siding with the disabled person in this case people with mental illness. Another principle discussed by Barnes (2001) is the choice of methods. As discussed in section 3.1, qualitative research has been used in this study since it provided the research participants with the opportunity to give detailed accounts of their lived experiences. The fifth principle is giving primary importance to the experience of disabled people. The use of IPA ensured that the lived experiences of people with mental illness and
their families was given its due importance. Lastly, emancipatory research should provide practical outcomes for people with disability, in this case people with mental illness and their family. The practical outcomes in this study were aimed to shed light over mental illness in general and findings will aim to help service providers and users in the area of mental health. Through the research process, people with mental illness and their family members should be empowered with reference to their interests and needs (Barnes, 2001) by trying to minimise stigma as much as possible. Both parties will also benefit from better treatment and coping strategies.

3.9 Conclusion

This chapter outlined the methodological map of the research. The approach of the study was a qualitative one with Interpretative Phenomenological Approach being the methodology used. The methodological frameworks, namely the social model of disability and phenomenology were also discussed in this chapter. Interviews with open-ended questions were used as a method for this study as it aided participants to give a broad account about their lived experiences with mental illness. The following chapter will present the findings from these interviews along with their analysis.
Chapter 4

Results and Discussion
CHAPTER 4: RESULTS AND DISCUSSION

4.1 Introduction

The results together with the interpretation and analysis of the results will be presented in the same chapter to give a better understanding and interpretation of the themes that evolved from the interviews. The main points that will be discussed in this chapter include stigma, the mental health sector especially Mount Carmel Hospital, employment, quality of life, media and the services. The phenomenological concepts used for the study will also be applied to these themes. Even though this research studied two perspectives, that of people with mental illness and those of their relatives, there were several commonalities. The predominant one was stigma. Both spoke about how this stigma affected the person with mental illness in several aspects of his/her life. This will be further discussed later on in this chapter.

The two tables below give an overview of the participants. Pseudonyms are used in order to protect their identity.

<table>
<thead>
<tr>
<th>Name</th>
<th>Male/Female</th>
<th>Age</th>
<th>Work</th>
<th>Mount Carmel Hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maria</td>
<td>Female</td>
<td>34</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Elizabeth</td>
<td>Female</td>
<td>55</td>
<td>Housewife</td>
<td>Yes</td>
</tr>
<tr>
<td>Suzanne</td>
<td>Female</td>
<td>60</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>John</td>
<td>Male</td>
<td>68</td>
<td>No</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Table 2: Family members

<table>
<thead>
<tr>
<th>Name</th>
<th>Male/Female</th>
<th>Age</th>
<th>Relation</th>
<th>Work</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mario</td>
<td>Male</td>
<td>63</td>
<td>Father of Maria</td>
<td>Retired</td>
</tr>
<tr>
<td>Jeffrey</td>
<td>Male</td>
<td>57</td>
<td>Husband of Elizabeth</td>
<td>Yes</td>
</tr>
<tr>
<td>Josephine</td>
<td>Female</td>
<td>54</td>
<td>Sister of Suzanne</td>
<td>Yes</td>
</tr>
<tr>
<td>Manuel</td>
<td>Male</td>
<td>48</td>
<td>Brother of John</td>
<td>Yes</td>
</tr>
</tbody>
</table>

4.2 Dasein, Mitsein and Sorge

During the discussion of the themes, I will be making reference to Heidegger’s concepts of Dasein and Mitsein. As already described in Chapter 1 and Chapter 3 Dasein is the being-in-
the-world of an individual, and Mitsein is the being-with (Moran, 2000). In this study, Dasein is being-in-the-world with mental illness and refers to the lived experiences of people with mental illness. On the other hand, Mitsein is being with someone who has a mental illness and refers to the lived experiences of the family members.

Being-in-the-world, being with things and being with others are all structured by the aspect of Sorge or care (Moran, 2000). Human beings are not meant to live in isolation. Apart from trying to understand ourselves, we try to understand one another even if sometimes this may be difficult. Most of the time we do this through caring for one another, therefore the concept of Sorge. As cited by Moran (2000), “Dasein has either chosen these possibilities itself or got itself into them, or grown in them already” (p. 239). The possibilities that Moran referred to in this quote refer to Dasein trying to understand its existence, that is the possibility “to be itself” or “not itself” (p. 239). As discussed before, as human beings we tend to inhabit an understanding of ourselves and of others especially if those with whom we share a lived experience. In this study, people with mental illness and their family members shared the lived experience of mental illness. Through the interviews, they disclosed their world and their understanding of it, given a particular space (spatiality) and time (temporality). Reference to these lived experiences will be discussed in relation to these concepts.

When asked about their lived experience, the family members spoke more about the impact of mental illness on their relative with mental illness rather than how mental illness affected them personally. This indicates that their experience is more about care (Sorge) and empathy towards their family member with mental illness. Rather than experiencing barriers themselves directly, the family members were more affected by how other people treated their relative with mental illness. This concept of Sorge will also be discussed further in this chapter.

4.2.1 ‘Geworfen’

Dasein, Mitsein and even Sorge are in a way ‘thrown’ in a society where stigma and discrimination are dominant factors and where mental illness still imposes negative stereotypes such as craziness, dangerousness and madness. Therefore, there is also an element of ‘thrownness’ (Geworfen) as discussed by Heidegger, in the lived experience of the research participants. One is absorbed in the world and the everyday mood of an individual depends on tasks. As stated by Moran (2000), “we don’t reflect on who we are, we are ‘thrown’” (p. 242).
As can be seen from the analysis below, the being-in-the-world of people with mental illness is infused by stigma. Stigma, as will be discussed in this chapter, permeates the being-in-the-world of people with mental illness. It is as if in the same way that we inhale and exhale air, people with mental illness breath stigma in and out, as it surrounds their world.

This sense of ‘throwness’ is affected by spatiality and temporality. Spatiality refers to the spaces to where a person with mental illness belongs, in this case Malta. On the other hand, temporality refers to a specific period of time, in this case being the early 21st century. In his book ‘Being and Time’ Heidegger explained ‘everydayness’ as a mood where information is passed on from one generation to the next (Moran, 2000). This may be a reason why stigma is still present in our society and might still be in the future. There is therefore the impact of the past on the temporality of the present, which is carried into the future. This barrier of stigma is a way of being in the lived experience of people with mental illness and their family members as it is present in several aspects of their lives as will be seen in this chapter.

4.3 Stigma and the Yo-Yo effect

The single most dominant factor that came out from the interviews was the experience of stigma. As such from the study it was noted that the only barrier in any aspect and lived experience of people with mental illness, was stigma. Stigma always rebounds back to the person with mental illness, as can be seen in the figure below. It is like the string of a Yo-Yo, always rebounding back and forth between the person and society.

![Figure 1](image-url)
The reply to the question about how the participants think that people with mental illness are perceived in society was that they are stigmatised in society. In fact, Maria discussed that the public perceive her as unable to make a contribution as they think that people with mental illness are always depressed. She feels that stigma is present in all aspects of society including hospitals and in the workplace. Josephine stated that the presence of stigma has limited her from going out as she feels that people are staring at her and abuse her when they know that she has a mental illness,

people abuse in a way that continue to ask you for money and they never return the money back, they always tell you for example, one case for instance there was a lady who had two young children, her mother used to take care of them, she used to tell me give me some money for the nappies, for milk, and little by little the money increased but she never gave me the money back.

John stated that the general public instead of encouraging him to move on with his life, they labelled him as being “sick in the head”. People with mental illness also feel that they are limited in certain things they say as people label and discriminate them due to their mental illness.

The family members of people with mental illness also discussed the impact of stigma on their relative. When asked about the effects of stigma, Mario said that “both me and herself [daughter] feel that she has a low self-esteem due to the stigma”. He claimed that his daughter does not feel like everybody else and that “everyone will be looking at her, as people know that she is different”. Jeffrey also stated that people label his wife as “mad and crazy”. Josephine feels that she experiences stigma herself when people know that she has a family member with mental illness, “they stare at you, they give you that gaze”. She claimed that whenever people see her sister in the street, they are afraid of her as they think that she is going to hit them or even “kill them, because of her madness”.

As already mentioned, the barrier of stigma to people with mental illness can be described as a Yo-Yo effect. It will be noted in the next sections that when discussing the various themes, stigma is always the reason why people with mental illness are faced with barriers in society, and hence why it can be said that there is a Yo-Yo effect. Everything eventually rebounds back to stigma and stigma seems to be the starting point of most problems. As discussed in Chapter 2, people with mental illness have been portrayed negatively in society for a long time.
(Mondimore, 1999). It was during the nineteenth century that Baillarger and Falret connected mania and depression and came up with the idea of mental illness (Mondimore, 1999). Nowadays, mental illness has been accepted more in society including Malta (Laws of Malta, 2012). The new Mental Health Act (2014) repealed the old one and is more attuned towards the rights of people with mental illness. However, the effects of stigma still persist as can clearly be seen in the lived experiences of people with mental illness in this study in different aspects both on a personal level such as in the quality of life and even on a societal level for instance employment and the media. However, this is not the case in services that are socially oriented. In this sector, attitudes towards mental illness are different therefore, the lived experiences of both people with mental illness and their relatives differ in being more positive. The aspect of socially oriented services will be discussed further in section 4.8. To sum up, the living with stigma all the time and its effects is not inevitable, but it all depends on the attitude towards mental illness.

As Suzanne stated, “[p]eople see me as if I’m an alien”. Here there is a connotation that having a mental illness is something out of this world and again it is all inflicted by stigma. There are two types of stigma which emerge clearly from this study. These are self-stigma and structural stigma (Overton & Medina, 2008). The Yo-Yo effect (figure 1) is evident again here because either way, stigma rebounds back to the person with mental illness. Structural stigma may in turn lead to self-stigma which again eventually rebounds back to the individual as explained in the figure below.

![Figure 2](image-url)
Firstly, self-stigma is a form of evaluation where the individual judges him/herself, and which is influenced by attitudes from societal norms (Overton & Medina, 2008). This type of stigma leads to low self-esteem in individuals and makes them feel as if they are incapable of functioning in society and living up to its expectations. When Suzanne, who is a person with mental illness was reading about mental illness, she used to feel that she was different from her family and friends. As she stated, “I used to feel the things I was reading. It made me feel different and I knew that there was something wrong with me so I was isolating myself from others because I knew I wasn’t normal”. Going back to Dasein, a person with mental illness questions his/her very existence in society, and in turn questions the very nature of their being (Overton & Medina, 2008). This self-stigma experienced by people with mental illness is influenced because we tend live with and compare ourselves to others. In addition to this, as explained in figure 2, structural stigma such as in employment may trigger the person with mental illness to self-stigma since when excluding him/her from society, it automatically makes the person feel different and ‘not normal’.

When there is an evaluation of an individual, most of the time s/he is compared to societal norms (Davis, 2006). And it is when society recognises a person as ‘not normal’, that barriers are created. Goffman describes this as structural stigma (Overton & Medina, 2008). This is again affected by spatiality and temporality as it reflects where people with mental illness belong in a given society. As cited by Overton & Medina (2008), “[p]eople with mental illness may have difficulty finding their function or a sense of place in the intersubjective world” (p. 144). Structural stigma may be influenced by economic and political factors as well as by culture (Corrigan, 2004). Discrimination and stereotypes, as seen later in this chapter rob people with mental illness of opportunities. As John mentioned, “people think I’m a crazy person and they think I am not capable of anything. They give me the worse job”. The structural stigma in employment will be discussed further in this chapter.

4.3.1 The Stigma Process

In accordance with the study by Corrigan (2004), structural stigma is a process, with the recognition of cues being the first part of the process. As already discussed, people with mental illness are labelled negatively as soon as they are diagnosed with a mental disorder (Granello & Wheaton, 2001). This is often the first cue. After this, the second part of the process starts with stereotypes being activated and implemented to an individual’s thought process. As seen
in my findings, these stereotypes are usually negative ones with ‘crazy and mad’ being the most common labels. These labels feed into prejudice and discrimination which is the third part of the stigma process. As Maria described, “[p]eople are afraid of me and don’t stay with me because they think I’m different and am not able to render a service in society. So they don’t speak to me”. Furthermore, as stated by Josephine in section 4.3, discrimination leads to the strong emotion of fear, thereby continuing to increase further the social distance (Corrigan et al., 2001).

4.3.2 “I feel saddened and angry”

As mentioned in section 4.2, the concept of Mitsein is used here to refer to the family members of people with mental illness. The relatives can also be referred to as the ‘others’ and there is the strong element of care and empathy towards the person with mental illness. As seen from the previous paragraphs, the family members explain the experience of their relative with mental illness rather than how mental illness affects them personally. They did not say that they experience stigma but are affected when their family member with mental illness is stigmatised. As Josephine stated, “it doesn’t affect me if people stare at me, but I feel saddened and angry when I know that they are talking behind my sister’s back because she has a mental illness”. The sense of care is also mentioned in the article by Chadda (2014) where he explained that family members are the primary caregivers for a person with mental illness. They aid in the day-to-day care and in the administration of medicine, look after the financial needs of the person with mental illness and also bear the behavioural disturbances of the person with mental illness. Heidegger explained that Dasein is influenced by the way one lives with ‘others’ and all this is based on care (Sorge). “As Heidegger puts it, the existential meaning of Dasein is care” (Moran, 2000, p. 238). To take up the concept of Geworfen again, the family members are in a way ‘thrown’ into a situation where they have to look after their relative with mental illness. Their lived experience revolves around caring for their relative and in a way, protect them from the stigma that is imposed on them by the general public. The quality of life and the coping strategies of the family members will be explained further in section 4.6.

4.4 The Mental Health Sector

All participants said that admission to Mount Carmel Hospital exacerbated the effects of stigma. Both people with mental illness and their family members had negative comments
about the hospital and experienced negative attitudes from the public when knowing about their admission there. As mentioned earlier in section 4.3, the main barrier of the lived experience of people with mental illness is stigma and as explained it is shown in different aspects, one of them being the mental health sector. This is instantly shown from the moment of admission to Mount Carmel Hospital and the attitudes from health care professionals in the sector. Elizabeth refused to be admitted to MCH at first because of the stigma and claimed that she “prefers being called an alcoholic rather than a person with mental illness or a person who has been admitted to Frankuni”. I will be returning to the use of the name ‘Frankuni’ later on in section 4.4.1. The fact that Elizabeth preferred to be called an alcoholic implies a type of hierarchy which makes mental illness look worse. Being an alcoholic has negative implications. Elizabeth’s classification puts a darker shadow on mental illness as it is placed lower in the hierarchy. Three family members mentioned the fact that if their relative was admitted to Mount Carmel Hospital s/he was immediately labelled as “crazy” whilst if a patient has cancer and were admitted to the Oncology hospital or to Mater Dei (the general hospital), the general public reacts differently and show pity towards them.

Four participants also emphasised the point about Mount Carmel’s environment which is on the less side attractive when compared to other hospitals such as Mater Dei. They claimed that the place itself is not appealing but has improved slightly nowadays when compared to 20 years ago. One family member admitted that when once he visited his relative at MCH, there was “even vomit on the window sills”. Two people with mental illness also mentioned the fact that the place is dark and makes them feel even more depressed. Again, it all depends on the spatiality and the temporality. When considering spatiality, Mount Carmel Hospital has improved for the better in the 21st century when compared to the 19th century. If people were admitted to a psychiatric institution in the 19th century, the stigmatising effects would have been worse and they were treated as insane. The environment conditions were dark and the place was tremendously dirty and inmates were usually chained to the walls (Savona-Ventura, 2004). According to the participants in this study, this mentality and the conditions of Mount Carmel Hospital have changed for the better nowadays even though there are still some cases of assault and confinement.

Maria stated that she experienced stigma from health care professionals in Mount Carmel. “In Mount Carmel, the nurses do not treat the patients very well, and they say because he is mad and they cannot do anything about it. They give up on the person very easily”. Apart from
health care professionals in Mount Carmel Hospital, Manuel experienced stigma from his family doctor. He stated,

One day I remember, there was an episode, how long was it maybe 3 years ago, and I was a bit down. I was passing through some tough situations and I went to my family doctor because I had the flu and I told him, because I also feel a bit depressed sometimes, and I told him that. And he told me but I am not going to mention anything like that on the sick leave certificate. And I told him but why? And he told me of course no! Otherwise people from work will label you that you’re mad and that you have a mental illness. I mean these are not my words, but the doctor’s words. You see the stigma!

This shows how stigma is also present from professionals as well apart from the general public. This lived experience also shows how the family member was indirectly affected by stigma”.

4.4.1 The Admission to ‘Frankuni’

As discussed in chapter 2, the word ‘Frankuni’ carries extremely negative associations with it. I chose this word because to the participants, the experience of stigma continues to grow once the person with mental illness is admitted to Mount Carmel Hospital and in fact, more than one participant used this connotation of Frankuni. Again, stigma is very pervasive here. Admission to a psychiatric hospital is targeted to treat a person, in the same way that when a patient with heart problems is admitted to Mater Dei hospital to get the appropriate care. However, the string of the stigma Yo-Yo rebounds back again on the person here because, while they do get the care they need, their admission at Mount Carmel exacerbates this social barrier of stigma.

As seen in the previous section, there has been a whole evolution when it comes to mental health in Malta. One participant stated that Mount Carmel is not given much of a priority when compared to Mater Dei Hospital. Manuel argued that mental illness provokes revulsion:

When a person gets sick with another condition, for example God forbids, gets sick with cancer, other people show sympathy towards that person. If someone gets sick with cancer, people say ‘Oh what a pity (miskin), how sad. How can I help them?’ However, when a person gets sick with a mental illness, people think that it is that person’s fault. They think that s/he is mad and it’s all his fault. They call them names and so on.

The concept of Geworfen, comes into play again as we are thrown in a society where as previously discussed, Mount Carmel Hospital is still being stigmatised and unacceptable, whereas other hospitals such as Mater Dei are acceptable and non-stigmatised. The ‘air’ that
surrounds an institution like Mount Carmel is stigma which provokes revulsion. This stigma is part our everydayness in our particular culture (Moran, 2000). Since our everydayness is transmitted from one generation to the other, there is still that stigmatising effect when someone is admitted to a mental institution. Therefore, it can be noted that the present temporality is impinged upon by the past. Here the Yo-Yo effect comes into action because as soon as someone is admitted to Mount Carmel Hospital or as some people still call it Ta’ Frankuni, s/he is already being stigmatised that s/he is mad and crazy and should be isolated from society. The ‘throwness’ for patients at Mount Carmel is in a way complete since it is not just a matter of perception of stigma as it is for the rest of the population, but a question of being immersed in that stigma, of being ‘thrown’ into the very institution from which the stigma emanates.

The maltreatment of people with mental illness has been augmented by the negative stereotypes that has been imposed to them since past times. Stereotypes such as being incompetent and dangerous often lead to the person with mental illness being deemed as unfit and not able to function in society (Gostin, 2008). As stated previously, stereotypes depend heavily on temporality. In accordance with Gostin (2008), health services for people with mental illness up till the mid-20th century were given in Victorian-like institutions. These institutions were costly, promoted isolation and neglect and were at times abusive on the person with mental illness, and it was in the 1960s that civil rights advocates fought to close these psychiatric institutions (Gostin, 2008). Mount Carmel is itself a Victorian hospital. Since that time, conditions in this (Mount Carmel) hospital started to improve. For example, the way treatment is administered has changed for the better and therefore this positive change was affected by temporality. On the other hand, according to the findings in this study, stigma still persists and so it does not seem to be so much affected by temporality. As stated by Manuel,

Things at Mount Carmel have improved a lot since the past 20 years ago, however still, it is not given much attention and priority as Mater Dei. And I know why. It’s because this type of illness only affects a small population so people with mental illness are in a minority. Even in the eyes of the political parties.

As seen above, there are already negative implications when one is admitted to a mental institution. Apart from the general public, negative attitudes are also present from the health care professionals as will be seen in the next section.
4.4.2 Negative Attitudes of Health Care Professionals

The Yo-Yo effect comes into evidence again when the participants spoke about the stigma they face from the health care professionals including some of the nurses at Mount Carmel Hospital and also the general practitioner mentioned by Manuel. This stigma from the health care professionals is also evident in the claim made by Maria in section 4.4, where she claimed that she was maltreated by the nurses in Mount Carmel and considered her to be insane. It is also noticeable in the study by Pellegrini (2014) where she reportedly stated that people with mental illness feel “patronized, punished or humiliated” (p.1) by health care professionals. Negative stereotyping, as has already been mentioned, is one of the main reasons why professionals stigmatise people with mental illness. This stereotyping can have a negative impact on the person with mental illness when seeking treatment. In their study, Corrigan, Druss & Perlick (2014) commented that due to the stigma, people with mental illness tend to limit themselves from receiving mental health care, which in a way becomes a form of self-stigma. A study by Thornicroft, Rose & Kassam (2007) found out that general practitioners and physicians are more stigmatising when compared to psychiatrists and often adopt a negative attitude when treating a person with mental illness. Here I can refer again to Manuel’s experience when visiting his family doctor. It is interesting to note that Manuel is not a person with mental illness himself but still felt the negative perception claiming that “[i]t would have been worse if this happened to my brother, as he [the doctor] would have made him feel worse” and again rebounding the string of the Yo-Yo back to the individual with mental illness.

The stigmatising effect that has been described in this section can continue to give rise to further structural stigma as will be discussed in the aspect of employment. The negative stereotyping may be transmitted in the place of work where it may eventually result in discrimination and downgrading in the workplace as will be seen in the next section.

4.5 The Hierarchy in Employment

A strong shared experience that came out from the interviews with both people with mental illness and also their relatives was that persons with mental illness are downgraded in the workforce. They feel that they are not given much dignity and that employers think that they are not capable of performing well at work due to their mental illness. They also mentioned the fact that people with mental illness are not paid the same as other people who do not have a
mental illness. It is significant that almost all the participants felt the need to emphasise that if a person has a mental illness, it does not mean that s/he is not intelligent or bright. John felt that he was the subject of prejudice when he used to work. One experience that he shared was when he used to work in domestics and he was mistreated.

I was the lowest worker there. They didn’t even provide me with a spade. I used to pick up dirt from the floor with my hands. I used to gather the dirt with a broom, because I was a cleaner, and then I used to pick it up with my hands. I used to get the bin beside me, pick up the dirt with my hands and throw it in the bin.

Furthermore, the fact that people with mental illness had difficulty finding employment affected the financial situation of the whole family. Jeffrey said that he had to do two jobs in order to keep up with the bills and to continue supporting his wife, otherwise they wouldn’t have a chance to keep up with the costs of daily living. Two family members pointed out the fact that sometimes the mental illness itself does not let the person go to work because they feel so depressed and sick. This therefore continues to show how income is affected negatively by the mental illness. According to Mario, “the person who is mostly affected by poverty is the person with mental illness himself or herself”. In fact he claimed that if it weren’t for his financial support and that of his wife, their daughter would have found it very difficult to cope and pay for her medications and the psychiatrist.

4.5.1 Spaces where a Person with Mental Illness belongs in Employment

As seen from the above shared experiences, people with mental illness are placed the lowest in the hierarchy of impairments (Deal, 2003). They are downgraded and rejected when it comes to finding a job and are ‘thrown’ into the worst part of the job even if they have more capabilities. Dasein, being defined as the embodied being, depends on spatiality (Moran, 2000), in this case the workplace. As Batastini, Bolanos & Morgan (2014) argued, employment gives a sense of importance and achievement to the person. Therefore, one can say that employment is part of the everydayness of a person. As seen from this study, the participants with mental illness had negative experiences in their place of work and this affected their being-in-the-world. The Yo-Yo effect discussed in section 4.3 is clearly visible again here as barriers to employment are first and foremost due to stigma on mental illness. Like the string of the Yo-Yo, as soon as the individual with mental illness is included in society by finding employment,
it rebounds back on him/her because due to stigma s/he is still being maltreated in the workplace.

Referring back to Chapter 2 section 2.7, 50% of people with mental illness in Kumar & Frangou’s (2010) study were working below their qualification standards and were mistreated in their work. This was evident in my findings as well. As a family member stated,

[y]es for sure people with mental illness are downgraded when it comes to employment. They are not given difficult jobs to do as they (referring to the employers) do not trust them.

In their study, Batistini, Bolanos & Morgan (2014) claimed that people who have a mental illness are labelled as idle and earn less income than other employees. However apart from the stigma itself, barriers in employment may be the result of other factors such as impairments resulting from the mental illness itself, and the diminished interpersonal skills and cognitive difficulties (Batistini, Bolanos & Morgan, 2014). This was claimed by Mario who stated, “she [his daughter] is a very bright girl in fact she is a beauty therapist but how do you expect that she goes to work when the mental illness makes it difficult for her to work?” This lack of motive to work might eventually lead the family into poverty especially because they are not entitled to the disability pension. This impact of poverty on the family will be discussed further in the next section.

4.5.2 Added Care Responsibilities

There is a strong link between mental illness and poverty and people with mental illness are more likely to experience poverty (Borton, 2015). As stated previously, having a mental illness, can have adverse effects that prevent the person from entering the workforce, especially since social stigma is always present. S/he is ‘thrown’ in a world which sometimes, due to the mental illness, makes the person incapable of working. In fact, the rate of unemployment in people with mental illness is lower when compared to people with physical disability (Borton, 2015). This all leads to low income and poverty for the individual with mental illness and may in turn lead to stressful consequences on his/her family. Several participants who are the family members of a person with mental illness commented on the financial situation and how they had to work several part-time jobs to support their family. As Mario claimed “it is because both
me and my wife have a good pension that we are able to support our daughter. Otherwise it would be very difficult as she doesn’t work anymore”.

Poverty in itself is stigmatising. And, apart from having a social impact, stigma also have materialistic impact on the family which affects their lived experience because it is now affecting the material aspects of their lives, in this case because of a lack of money. The family has added care responsibilities therefore the aspect of Sorge is present again here. This will also be seen in the next section which is based more on the person with mental illness therefore being more on a personal rather than social level.

4.6 When “the bike doesn’t continue turning smoothly”

A prevalent experience that was shared by both people with mental illness and also by family members was the impact on the quality of life and the state of health of the person. All four people with mental illness claimed that the illness affected them during their childhood and their youth as they felt that they were different from others. Suzanne argued that she was restricted in doing certain things as she felt that

it seems that if there are two persons, one tells you do the work whilst the other tells you don’t do anything, or you feel that you are being attracted to both and you cannot decide what to do, your mind doesn’t let you, if it says no it’s a no.

In fact, this thought led her to being shunned by her friends as they too thought that she “was different”. Elizabeth commented that she couldn’t cope with her daily responsibilities and this affected both her and her family members. She claimed that her family were ashamed of her and they did not speak to her, which affected Elizabeth very negatively and left her feeling devastated. John stated that the mental illness altered his character traits and affected his daily routine. He stated, “I was lost and sometimes I was very frustrated and sometimes I even started screaming or did something very stupid. But then I calm down”.

Family members of people with mental illness also experienced disruption in the daily routines and the mental illness on their relative left an impact on their quality of life as well. Two family members claimed that they needed to make adjustments in their daily routine such as having to wake up early since their relative wakes up early. Mario also claimed that he has to take his
daughter out almost every day because if not she will rebel against him and his wife. Their morale is very much affected by the mental illness. Manuel said,

[m]aybe you wouldn’t be affected as much as the person with the mental illness but still depression attacks you and when you see someone in your family being affected so bad, it makes you feel very down.

In section 4.2, it was pointed out that the family members’ lived experience is that of Mitsein. However, as seen from the finding above, there are also instances where the mental illness has a direct impact on the family members’ lived experiences, albeit to a limited extent. He describes that, “the bike doesn’t continue turning smoothly” and mental illness “destroys everything around it”. Mario and Manuel, who are the relatives of a person with mental illness, both discussed how their general and mental health being were affected. During the interview, they mentioned that apart from their family member with mental illness, they too were sometimes affected negatively and feel depressed. Mario admitted that the stress that was imposed on his family due to having a daughter with mental illness, resulted in his developing a heart condition and eventually he had to undergo a bypass operation. In contrast to what these family members said, Jeffrey was more positive when asked about the quality of life. He stated that his quality of life and the state of his mental health being became stronger, in fact he stated that “someone of the two must remain strong in order to support the other one”.

Mental illness in itself brings disruption to a person. This disruption is aptly compared to the malfunctioning bicycle by Manuel. One day the person is leading a normal life but then the next day something abruptly happens such as mental illness and disrupts that routine. This disruption in the being-in-the-world of an individual results in the disruption in his/her lived experience, like a “bike that doesn’t continue to turn smoothly”. As a result of this disruption, the possibilities in that person’s world change completely. I will be expanding on this aspect in the next section.

4.6.1 Difficulties with Coping

As seen in the previous sections, the being-in-the-world of people with mental illness is affected by the mental illness itself. As cited by Moran (2000), “Dasein always understands itself in terms of its existence …. “Dasein has either chosen these possibilities itself or got itself into them, or grown up in them already”. As seen from the previous section, the impact of
Mental illness has been ‘thrown’ on the person and becomes part of their everydayness, which is then changed because of the mental illness. Here, one can again refer to Manuel’s image of the bike that stops turning smoothly. The nature of Dasein therefore also changes, because the terms of its existence change with mental illness. Mental illness changes the lived experience of a person because everything revolves around it and around the stigma that is brought with it. It is like the air they breathe, the mental illness and the stigma are always present in their world. As Heidegger explained, human beings adopt an understanding about themselves (Moran, 2000), but as seen from the findings in this study, it is difficult sometimes for a person to know his true self especially when the mental illness has such an impact on their state of mind. The quality of life which is a substantial aspect of a person’s life, forms a great part in the lived experience of a person with mental illness. Referring to Suzanne’s quote in section 4.6, about the mental illness, she is in a way trying to understand herself and what is happening around her but the mental illness makes it difficult for her to choose and ultimately reduces her quality of life and finds herself in isolation. Here one can again refer to figure 2, where it shows the string of the stigma Yo-Yo rebounding back and forth from Suzanne because she experiences self-stigma.

As discussed in section 4.2, the concept of Mitsein refers to the family members of people with mental illness as they are the ‘others’. However, as seen from the findings in this section, the nature of Dasein can be referred to the family members as well, as the mental illness in their family affects their quality of life directly as already discussed in section 4.6. As seen in this section, their general health was affected with one family member claiming that he too feels depressed at times and the mental illness disrupts his routine. The sense of care and empathy towards their relative with mental illness in a way diminishes a bit here because the family members’ lived experience is directly influenced by the mental illness and required care themselves, as in the case of Mario when he had spoken about the stress that mental illness has caused him. However, the quote by Jeffrey in section 4.6 again shows that even though the family members’ encounter negative lived experiences due to the mental illness, the sense of empathy is still in the person’s nature as at the end of the day the family members are the primary carers of the person with mental illness even though it may cause them stress and frustration. As can be seen in this section, the family members had to adapt as they had to be strong because of adversity, both for themselves and even for their relative with mental illness. The family members had to be strong because of how the mental illness affected their relative not just because they had to be strong. The disruption of the family members’ being-in-the-
world is evident here as the bike didn’t continue to turn smoothly for them either therefore continuing to affect their lived experience.

4.6.2 Quality of Life

Having a severe mental illness affects a person’s quality of life directly and can result in long-term consequences on the social functioning of a person (Jonsson, Skarsater, Wijk & Danielson, 2011). In a study carried out in the Maltese context by Borg et al. (2011) one of the participants described the experience of having a mental illness as “hitting the wall” (p. 1). To link this quote with Manuel’s quote “the bike doesn’t continue to turn smoothly”, they are basically saying the same things. Mental illness comes about so suddenly that it changes the person’s being-in-the-world and the lived experience of the individual. The same happens to people when they face mental illness. At one point, the person with mental illness is functioning smoothly in society and seems to be walking down a straight road when suddenly s/he hits a wall and there is disruption in his/her daily routine. This example can also be compared to Manuel’s quote of the faulty bike. The impact of unemployment, isolation, low quality health care and interruptions in daily living all affect the quality of life of a person with mental illness. These mostly come about due to the barrier of stigma. The string of the Yo-Yo is constantly rebounding back and forth to the individual with mental illness because in any aspect of his/her life, s/he is faced with stigma that continues to exacerbate the effects of mental illness on the quality of life. This is where the element of care and empathy by the family members come in (Jonsson, Skarsater, Wijk & Danielson, 2011), as they now need to take over the situation because their relative with mental illness is not able to cope well due to this disruption in the quality of life. This disruption also affects the quality of life of the family members as they will need to adapt to the situation which changes so suddenly for them as well.

As seen from the results discussed in section 4.6, a family member (who is caring for a relative with mental illness), experiences dramatic changes in his/her life as well which includes several illness-related challenges, as in Mario’s case. The fact that the family members have to sustain the financial situation of the family and some of them even had to work two jobs, increased the stress levels and further increased the burden on their own health and quality of life (Jonsson, Skarsater, Wijk & Danielson, 2011). This burden therefore causes a disruption to the family’s being-in-the-world as well and so the bike doesn’t continue to turn smoothly for them because their lived experience revolves indirectly around the mental illness.
4.7 Media Representations of People with Mental Illness

A significant thought shared by the participants was that the media still portrays people with mental illness negatively especially in films and in how certain comments are written in newspapers. People with mental illness and their families claim that certain movies show people with mental illness as mad, killers and people to make fun of. An interesting point made by three participants was that even in Malta, people who commit a crime are sometimes admitted to Mount Carmel Hospital and are diagnosed with a mental disorder. Suzanne argued, “[t]hat person should be placed where he is supposed to be not in Mount Carmel Hospital. He did a terrible act, it is not a simple mistake, it is a horrible mistake that of killing”. According to her, people who commit a murder would know what s/he is doing and “should not be diagnosed as being mentally disturbed but a killer”. The participants claim that these false allegations are shared by the media and continue to put people with mental illness under the dark shadow of stigma and “the general public would start to think that every person with mental illness is going to perform these horrible acts” as Mario stated. Again, one can make reference to the Yo-Yo effect but this time it differs a bit as the media is shared over a widespread population. This time, the string of the Yo-Yo is rebounding on/from the whole society not just sections of it such as employers, or health professionals.

On a positive note, participants pointed out that the media can be a means to educate the general public on mental illness through discussions, as is done with other conditions such as diabetes and heart disease. Two participants also stated the fact that celebrities can minimise the stigma about mental illness as people are “in a way influenced by them” as Jeffrey claimed. They all agreed that if the media is used correctly it can minimise the barriers that people with mental illness are faced with in their daily lives and therefore can cut the strings of the Yo-Yo as will be seen in section 4.7.2.

4.7.1 “A dark shadow on people with mental illness”

The media can be considered to be a form of spatiality as it is ubiquitous. Media may be present in several forms including newspapers, television programmes, movies, online articles and news and radio programmes. As stated by the participants, the media portrays people with mental illness negatively and this not only happens in foreign movies but is also evident in Malta as well. We are different to one another, however we experience similar thoughts and
ideas especially when something is portrayed to us via a common source, as in this case the media. As Heidegger described, when people pass information to one another they think that they have an understanding of one’s everydayness (Moran, 2000). However, this information might not necessary be concordant with facts. How the media portrays mental illness is not necessarily factual, therefore the media has a big impact on how the general public views people with mental illness. The everydayness of people with mental illness is very much affected by how information about them is transmitted to the public. As stated in the title of this section, the media may put a ‘dark shadow’ (as described by Suzanne) on people with mental illness therefore their being-in-the-world will have a dark shadow cast over it which eventually has an effect on the lived experience.

Our everydayness involves passing information to one another, but without actually getting involved in it. Our speech is in a way an ‘idle talk’ or Gerede in Heidegger’s words (Moran, 2000). We tend to comment without actually trying to experience the authenticity of the event. Heidegger described authenticity in terms of ownness or ownership in fact he stated that, “[m]y existence is something which is mine; or, put more generally, Dasein has the structure of ‘mineness’ (Moran, 2000, p. 239). In other words, we cannot really judge or portray people with mental illness negatively as we do not know their true lived experiences. It is only they who know their authenticity and their own being-in-the-world. The media does not have a real understanding of the everydayness of people with mental illness and therefore tends to be inauthentic on how it portrays mental illness but we tend to believe everything we see on the media. For instance, when a homicide occurs, the media instantly depicts the person as having a mental illness and this is then transmitted to the general public where they continue to portray a person with mental illness as being ‘violent’ and a ‘killer’ (Edney, 2014) and therefore putting them again under the dark shadow of stigma. Here we are in a state of ‘das Man’ in other words we tend to believe everything we see on the media and so we continue to be inauthentic as well (Moran, 2000). The string of the stigma Yo-Yo is again going back and forth to the individual from society because the media most of the time stigmatise people with mental illness, and so it is another impact on their lived experience and a further disruption in their being-in-the-world.

On the other hand, as seen in section 4.7, there is the projecting possibility that the media can be used as a form of education about people with mental illness for the general public. Apart from discussing what mental illness is, people with mental illness can use the media to share
their experiences and aid one another. The media can be a means to raise awareness about mental illness and hence change inauthenticity to authenticity and therefore another way to cut the strings of the stigma Yo-Yo and change the lived experience of the person with mental illness to the better.

4.7.2 The Media’s Power

To a large extent, the media has a great influence in developed societies and media representations can impact a wide population especially when it comes to mental illness. Dasein, referring to the lived experience of people with mental illness, can be harmed by the negative implications and inaccurate stereotypes often portrayed by the media (Buan, 2009). Here, one can again refer to the Yo-Yo effect discussed in section 4.3. As cited in a study by Rose (1998), media representations about people with mental illness were found to be so strong that they can actually supersede the person’s own experience in relation to how him/herself sees mental illness. In fact, referring to films involving people with mental illness, Suzanne stated,

even though I see them to be a bit extreme, when they tell you it’s based on a true story, I start to believe that I can end up like them one day. And this scares me. It scares me a lot, if it’s a true story.

The media can lead to self-stigma because as seen from Suzanne’s experience, she started to portray herself negatively as well, which eventually lead her to isolation as discussed in section 4.3.1. To go back to the point of inauthenticity, this is a perfect example of how people actually believe what they see, in this case not just the general public but the media also has a strong effect on people with mental illness themselves which continues to alter their being-in-the-world.

When a tragic or a violent event occurs, the news media tends to put a dull shadow on people with mental illness in blaming the act on them. Taking the Germanwings incident, as already discussed in section 2.6 of the Literature review, news coverage around the world referred to the pilot as “Madman in the Cockpit”. In their study, Schomerus, Stolzenburg & Angermeyer (2015) found out that the plane crash resulted in a severe impact on public attitudes towards people with mental illness. In fact, perceptions that people with mental illness are unpredictable
was noted to be increased in the general public after this incident. This was also very prevalent by the participants of the study, and as Suzanne continued to say with the previous quotation,

it’s not true what they show from movies. We aren’t really like that. It’s not true that a killer is a person with mental illness. They want to take the easy way out and say he has a mental illness.

Linking the two quotations by Suzanne together, they show that she is resisting the acceptance of the stigma that is imposed on her by these movies. In a way she is cutting the strings of the stigma Yo-Yo here because stigma is not rebounding back to her and therefore her being-in-the-world is not being effected.

Lastly, to take on the point about projecting possibilities discussed in section 4.7.1, the media can be used to send a positive message to the public and to educate people on mental illness. An interesting study carried out in the USA, showed that when viewing an empathetic movie of a person with schizophrenia, participants showed an increase in knowledge about mental illness. Apart from the knowledge acquisition, it has influenced the participants to reduce stigma on people with mental illness (Ritterfeld & Jin, 2006). Both people with mental illness and the family members stressed on this point and as Josephine stated, “like when there are programs concerning health issues, there should be programs that educate the public about mental illness. That could be one way how to decrease the stigma”. This change from inauthenticity to authenticity again is a projecting possibility where the lived experience of people with mental illness may change to the better therefore changing their lived experience to a more positive and less disrupted one. Another projecting possibility is present in the services for people with mental illness, which I will be discussing in the next section.

4.8 Socially Oriented Services

When using the term projecting possibilities mentioned above, I am referring to possibilities that decrease the stigmatising way how the general public views mental illness and that aid the lived experience of people with mental illness and their families to be less negative. Apart from educating the general public through the media as discussed in the previous section, socially oriented services are another possible way to project such possibilities. All but one participant made positive comments about the services offered to people with mental illness and their families. Two people with mental illness live in apartments offered by an NGO and said that
this NGO offered great help and guidance for them to be able to live independently rather than being admitted to an institution. Suzanne stated that this organisation helped her a lot throughout her worst times. “They even allowed me to get a rabbit as a pet which helped me a lot when I was depressed”. Both people with mental illness and their relatives had positive comments about the medical service in general such as social workers, psychiatrics and the entitlement of free medicines.

Mario, however, lamented the lack of services offered to the family members. As he stated, “it is very difficult and there is a limited number of services that help the family members of people with mental illness”. According to Mario, it is not the awareness that the family seeks but actually personal support as he claims that having a family member with mental illness is very stressful on the whole family especially the parents. He also mentions the fact that the NGOs for people with mental illness are not properly resourced and therefore may be limited to provide the maximum assistance.

As seen in the previous sections, the effects of stigma towards people with mental illness and their families were evident in all aspects of life both on a personal level and even on a societal level. This is however not the case when the participants were speaking about services that are socially oriented, as seen from the findings in this section. These services see the person as s/he is, irrelevant of his/her mental illness and without the barrier of stigma. This decrease in stigma by the services is a possibility that can have a positive effect on the lived experience of people with mental illness and their relatives. By creating different possibilities, the lived experience will be less stigmatising and less disruptive. The strings of the stigma Yo-Yo can be cut for a less destructive way of being-in-the-world for both people with mental illness and their family members. Further possibilities that will enable individuals with mental illness to live in a less stigmatising world will be discussed in the next section.

4.8.1 Projecting Possibilities

As already mentioned in Chapter 2, mental health support in Malta include three NGOs in all. Through these NGOs, as already discussed, there are already projecting possibilities in aiding the person with mental illness and his/her family members. However as seen in section 4.4, the participants stressed on the idea that if people with mental illness were admitted to Mater Dei Hospital instead of Mount Carmel Hospital, the way in which the general public portrays
people with mental illness would change for the better. Through this transition, there could be a possibility that the being-in-the-world of people with mental illness and their relative would be less stigmatising and therefore would be another form of how the string of the Yo-Yo can be cut. This was stressed a lot by Dr. John Cachia as will be seen in the next paragraph.

In Malta, the transition from having services at Mater Dei hospital instead of Mount Carmel, was the primary point on the agenda of Dr. Cachia, who is the Mental Health Commissioner and has been constantly fighting the stigma linked to mental illness. According to Dr. Cachia, mental health well-being should be a priority in electoral campaigns as he still considers that mental illness has severe awareness problems (Carabott, 2017). As mentioned by the participants of the study, Dr. Cachia also pointed out the fact that services for mental illness should transfer from a hospital-based to a community-based service in order to try and decrease stigma in Malta (Carabott, 2017). This could be a mean to ease the pressure on the person with mental illness and aids him/her to seek help earlier on.

As seen in chapter 2, through several studies it can be said that acceptance in people with mental illness has improved drastically when compared to past times even in Malta, as discussed in section 4.4.1. NGOs for people with mental illness are constantly working to improve their services. However there has not been enough research when it comes to supporting the family members of people with mental illness. As Mario stated, “it is not only the awareness that we seek but we seek personal help even more”. Another interesting point that Mario stressed was that NGOs should have not only voluntary people but also professional people such as social workers, in order to provide the best care for both people with mental illness but even more for their family members. According to Evavold’s study (2003), family members believe that there should be a family-centred care approach when caring and treating a person with mental illness. He continued to discuss that this family-centred approach will enhance the well-being of the person with mental illness and also their relatives and that health professionals should seek the presence of the family members when making decisions about the treatment and care for people with mental illness (Evavold, 2003).

Overall there was positive feedback when the participants were asked about the services in mental health. However, the effect of stigma may still exist within certain organisations because of an experience I have encountered. During my recruitment of service-users to take part in my study, I had a negative response when I contacted a certain NGO. As already
discussed in section 3.5 of the Methodology chapter, I was told by the representative of this NGO that it is difficult for people with mental illness to comply with an academic exercise due to their mental illness. In my opinion this gatekeeping issue is purely based on several negative misconceptions that are still being imposed on mental illness. People with mental illness, therefore are still ‘thrown’ in this dark shadow even by professionals in the mental health organisations sector.

4.9 Conclusion

As seen in table 1, people with mental illness all have a primary role in society being that of a daughter, a wife, a brother and a sister. Their identity however is affected by how others view the person with mental illness and what is expected from him/her in society. As seen in this chapter, stigma was a significant part of their lived experience of mental illness as it was encountered by people with mental illness and it was also felt indirectly by the family members. It was present in all aspects of their lives both on a personal level and even on a societal level except when it came to socially oriented services. Here findings showed projecting possibilities that aim at changing the being-in-the-world of people with mental illness to the better.

The nature of Dasein as explained by Heidegger highlights the uniqueness in every participants’ lived experience. The sense of care that was present by the family members shows us that one does not live alone and there is always the ‘other’ or Mitsein as Heidegger explains. It is also important to take into consideration the spatiality and temporality which is fundamental in one’s lifeworld.

The next chapter is the conclusion chapter which will sum up the findings and will also see the strengths and limitations of this study. In addition to this, I will be discussing some recommendations which can be used in further studies.
Chapter 5

Conclusion
CHAPTER 5: CONCLUSION

5.1 Introduction

This chapter will present and sum up the main findings of this interpretative phenomenological research in relation to the research questions below:

What are the experiences and the perspectives on life of people with mental illness?
What are the experiences and perspectives on life of family members of people with mental illness?
What barriers do people with mental illness and their family members face in society?
What support needs do they identify for themselves?

The strengths and limitations of the study will also be presented in this chapter together with recommendations that need to be put forward in future studies to improve the lived experiences of people with mental illness and their families.

5.2 Key findings

This study explored the lived experiences of people with mental illness and their family members. The concepts of Dasein, Mitsein and Sorge by Heidegger were discussed, with Dasein referring to people with mental illness and Mitsein referring to the family members. Dasein is the being-in-the-world and from this study I tried to get an understanding of the lived experience of people with mental illness and what it is like to live with a mental illness. The family members are the main carers for their relatives with mental illness and the concept of care or Sorge in relation to them was very evident in this study.

The elements of spatiality and temporality together with personal characteristics all provided uniqueness to each person’s situation, but at the same time there were commonalities between the stories of the participants. The main barrier that came out from this study was stigma. The family members did not face stigma directly but they spoke more about the impact of stigma on their relative with mental illness. Stigma was seen as being present in almost every aspect of life both on a personal level and even on a societal level. The main themes that came out and discussed in this study were the different types of stigma, mental institutions, employment, the media, quality of life and socially oriented services.
In almost every aspect, the barrier of stigma was brought in, which showed how the lifeworld of people with mental illness is really engulfed by stigma. In fact, I used the image of a Yo-Yo to show my understanding of the participants’ interpretations of their lived experience. Referring to double hermeneutics, the Yo-Yo image is my second layer of interpretation. Stigma is always rebounding back from society to the individual and can be compared to the strings of the Yo-Yo. It can be said that the being-in-the-world of people with mental illness is infused by stigma. It can be compared to the air that we breath, in this case these individuals seem to breath in and breath out stigma.

As stated, the caring role (Sorge) of the others, in this case referring to the family members of people with mental illness, was evident in this study. This supportive role was noticeable as the family members all mentioned how they were negatively affected because of how their relative with mental illness is treated in society including by some health care professionals. Their life experience was compared by one participant to a bike which does not continue to turn smoothly because they are suddenly faced with the impact of mental illness.

Mental illness is lived through as part of the participants’ lifeworld with stigma being prevalent in every aspect of life. However, this is not the case in the socially oriented services. The attitudes towards mental illness here are more positive and therefore the lived experience of people with mental illness and their relatives is different. This shows that the strings of the Yo-Yo can be cut and that living with stigma and its effects is not an inevitable outcome of having a mental illness. It all depends on social attitudes and how one perceives mental illness.

In this study, there were projecting possibilities that can decrease the stigmatising way how people with mental illness are portrayed. The concept of projecting possibilities is another component of the double hermeneutic as it is my own concept rather than one that I elicited directly from the interviews. These projecting possibilities enable the string of the Yo-Yo to be cut, as it were. As seen above, the socially oriented services are one way to achieve these possibilities. The media can also be another possibility, when it is changed from being inauthentic to authentic and educate the general public about what mental illness really is. The transition of having services at Mater Dei Hospital from Mount Carmel could also be a way forward to decrease the stigma about mental illness. These projecting possibilities are returned to in the recommendations section below.
5.3 Strengths and Limitations

In this phenomenological research, people with mental illness and their family members were actively involved throughout the research process. First I consulted with an activist in the mental health sector which lent the research emancipatory characteristics. All participants were able to highlight and share their lived experiences and what it means to live with mental illness.

Another strength of this study was that it identified the main barrier that people with mental illness face in society, which was stigma. The participants also identified the main aspects where stigma is mostly present together with an in-depth understanding of their lived experience. In addition to this, it gave Maltese people with mental illness a rare opportunity to make their voice heard through the research.

This study also highlighted what it means to care for a person with mental illness as the lived experience of family members who look after their relative with mental illness was also studied in the research process.

The main limitation of the study was that since it used a qualitative approach, a small sample size was used, meaning that one cannot generalise. However, the purpose of the study was not to go in that direction. It was aimed at studying in an in-depth manner the lived experience of the participants and focus on their day-to-day experience and therefore providing a holistic view of the participants’ reality.

Another limitation was that the participants were told beforehand that they will be audio-recorded during the interview, as is required by research ethics. This might have influenced them whilst answering the open-ended questions. The participants might have given the answer that they think that the researcher wanted to hear. However, I strove to overcome this by prompting the interviewee to provide detailed explanations of their experiences.

Biases from me, as the researcher, were always possible. This could also have been another limitation during the research process.
5.4 Recommendations

As seen from this study, family members require support as their quality of life is suddenly disrupted because of the mental illness. A participant from the study pointed out that there are lack of services for family members of people with mental illness. A recommendation for future research would be to have a deeper look at services which cater for people with mental illness but even more whether they cater for their relatives and the amount of support they provide these family members who care for their relative with mental illness.

Another recommendation would be to work on the projecting possibilities mentioned in the previous section. The media can be an important platform to raise awareness on mental illness especially since it is shared worldwide.

The participants of this study discussed that one way how to minimise the stigma that is constantly present in society is by having the services at Mater Dei Hospital rather than at Mount Carmel. This transition would decrease the ‘dark shadow’ that is put over people with mental illness and their relatives when they are admitted to Mount Carmel. A recommendation would be that NGOs for people with mental illness continue to work together with Dr. John Cachia (Mental Health Commissioner) for this transition to happen. Dr. Cachia insists that the transfer from a hospital-based to a community-based service for mental illness would decrease stigma in Malta (Carabott, 2017). According to the Health Minister, this is already being planned and is among the government’s projects for Mater Dei Hospital (Xuereb, 2017). This change might therefore lead to earlier detection of the illness and earlier intervention and support. With the aid of this study, I am hoping that service users’ organisations show an interest in using this work to create more awareness about mental illness. In order to maximise this, I will be disseminating a summary of the findings to NGOs and to Dr. Cachia himself.

People with mental illness should be included more in society and treated equally especially in the workforce. They should not be downgraded and should not work below their qualification standards. Employers should work more to aid people with mental illness in finding employment and decrease the taboo that is still very much present in the workplace. In addition to this, the media should ensure that it remains authentic when publishing stories about people with mental illness and should provide further education about mental illness.
5.5 Conclusion

This research has reached its completion. This study left a considerable effect on myself especially since I had an experience with mental illness within my family. Through this research process, I could relate to several lived experiences especially those of the family members but there is always room for further exploration and discovery about mental illness. I hope that through this study, the reader achieves new understandings about the being-in-the-world of both people with mental illness and their families and can get a clearer picture of what it is like to live with a mental illness. In addition to this, I wish that the taboo that still persists with mental illness will disappear, even if this scenario is still a long way ahead.
References
REFERENCES


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Appendices
8th January 2016

Dear participant,

Invitation to participate in a research interview

I am currently reading for a Masters Degree in Disability Studies within the University of Malta. As part-fulfilment of the requirements of the above-mentioned course, I am carrying out a research project entitled “The lived experiences of people with mental illness and the impact on their families”. The study will take place between May 2016 and April 2017.

The study aims to explore the lived experience and perspectives of people with mental illness and the barriers that they are faced with, in society. It will also be investigating the impacts on the family when one of its members has mental illness. I am inviting you to take part in an interview. Data will be collected through semi-structured interviews, at a venue of your choice. The interview will be conducted in Maltese or English, as preferred by you, and it will last between one or two hours. The interview will be audio recorded and notes will also be taken during the interview. When the interview is finished, the results will be formulated in the form of a transcript.

While this experience may be of benefit to you, there is no associated risk of harm lined with participation. Participation will be on a voluntary basis and it is reminded that you are free to withdraw from the study at any time and that the study is anonymous. A consent form will be signed prior to the beginning of the interview. All gathered information will remain confidential. Collected data will be kept in a safe place and will be destroyed at the end of the study. This information letter is being sent to you either via Richmond Foundation or the Mental Health Association Malta and St. Jeanne Antide Foundation.
Should you be interested in participating in this research study, you are kindly requested to fill in the acceptance form attached and send it in the self-addressed envelope provided with this letter.

If you have any questions, please do not hesitate to contact me on 79200993 or racheal.galea.08@um.edu.mt or my supervisor, Dr Anne-Marie Callus, on 23403689 or anne-marie.callus@um.edu.mt.

Thank you for your time and I look forward to meeting you.

Yours sincerely,

Racheal Galea (researcher)
‘THE LIVED EXPERIENCES OF PEOPLE WITH MENTAL ILLNESS AND THE IMPACT ON THEIR FAMILIES’ CONSENT FORM TO PEOPLE WITH MENTAL ILLNESS (ENGLISH VERSION)

I would like to participate in the research entitled “The lived experiences of people with mental illness and the impact on their families”.

I am aware that:

• Information will be kept confidential
• The interview will be audio-recorded
• I can choose not to answer certain questions
• I can withdraw his/her consent at any time
• All personal information will be kept confidential
• All recordings and transcripts will be destroyed after the end of the research.

Name & Surname

____________________________________________

Signature

____________________________________________

Date

____________________________________________

Signature of Researcher

____________________________________________
‘THE LIVED EXPERIENCES OF PEOPLE WITH MENTAL ILLNESS AND THE IMPACT ON THEIR FAMILIES’ CONSENT FORM TO PEOPLE WITH MENTAL ILLNESS (ENGLISH VERSION)

I would like my family member to participate in the research entitled “The lived experiences of people with mental illness and the impact on their families”.

I am aware that:

• Information will be kept confidential
• The interview will be audio-recorded
• I can choose not to answer certain questions
• I can withdraw his/her consent at any time
• All personal information will be kept confidential
• All recordings and transcripts will be destroyed after the end of the research.

Name & Surname

______________________________________________________________

Signature

______________________________________________________________

Date

______________________________________________________________

Signature of Researcher

______________________________________________________________
APPENDIX 1B – INFORMATION LETTER AND CONSENT FORM
FOR PEOPLE WITH MENTAL ILLNESS (MALTESE VERSION)

8 ta’ Jannar, 2016

Ghaziz/a partecipant/a,

Ittra ta’ Stedina (Verzjoni bil-Malti)

Jiena qieghda nsegwi kors f’livell ta’ Masters fl-Istudju dwar id-Dizabilita’ fl-Universita ta’ Malta. Bħala parti mill-kors imsemmi, jien se nagħmel studju msemmi “The lived experience of people with mental illness and the impact on their families”. L-istudju se jsehh bejn Mejju 2016 u April 2017.


Jekk inti interessat/a li tiehu sehem f’din ir-ricerka, inti mitlub/a timla l-formola ta’ approvazzjoni ta’ hawn that u tibghatha fl-envelopp provdut ma’ din l-ittra.

Jekk ghandek xi mistoqsijiet, jekk joghgbok tiddeijaqx tikkuntattjani fuq in- numru 79200993 jew racheal.galea.08@um.edu.mt jew lis- supervizur, Dr Anne-Marie Callus, fuq 23403689 jew anne-marie.callus@um.edu.mt

Grazzi tal-hin tieghek u nistenna minghandek.

Dejjem tieghek,

Racheal Galea (ricerkatur)
THE LIVED EXPERIENCES OF PEOPLE WITH MENTAL ILLNESS AND THE IMPACT ON THEIR FAMILIES’ FORMULA TA’ KUNSENS LIL' PERSUNI B’ MARD MENTALI (VERZJONI BIL- MALTI)

Jien nixtieq nippartecipa fl-istudju msemmi “The lived experiences of people with mental illness and the impact on their families”.

L-informazzjoni ta’ l- istudju ser tizamm b’mod kunfidenzjali
Il- partecipant/a j/taccetta’ li tigi rrekordjat/a
Il- partecipant/a j/tista’ jaghzel li ma jwegibx ghal certu mistoqsijiet
Il- partecipant/a j/tista’ j/tirtira’ mir-ricerka fi kwalunkwe hin

Isem u Kunjom  ____________________________________________

Firma                                          ___________________________________________

Data                                            ____________________________________________

Firma tar- ricerkatur                            ___________________________________________
‘THE LIVED EXPERIENCES OF PEOPLE WITH MENTAL ILLNESS AND THE IMPACT ON THEIR FAMILIES’ FORMOLA TA’ KUNSENS LIL PERSUNI B’ MARD MENTALI (VERZJONI BIL- MALTI)

Jiena nixtieq nati l- kunsens tieghi lil membru tal- familja tieghi biex j/tippartecipa fl-istudju msemmi “The lived experiences of people with mental illness and the impact on their families”.

L-informazzjoni ta’ l- istudju ser tinzamm b’mod kunfidenzjalij
Il- partecipant/a j/taccetta’ li tigi rrekordjat/a
Il- partecipant/a j/tista’ jaghzel li ma jwegibx ghal certu mistoqsijiet
Il- partecipant/a j/tista’ j/tirtira’ mir-ricerka fi kwalunkwe hin

Isem u Kunjom

__________________________________________________________________________

Firma

__________________________________________________________________________

Data

__________________________________________________________________________

Firma tar- ricerkatur

__________________________________________________________________________
Dear participant,

Invitation to participate in a research interview

I am currently reading for a Masters Degree in Disability Studies within the University of Malta. As part-fulfilment of the requirements of the above-mentioned course, I am carrying out a research project entitled “The lived experiences of people with mental illness and the impact on their families”. The study will take place between May 2016 and April 2017.

The study aims to explore the lived experience and perspectives of people with mental illness and the barriers that they are faced with, in society. It will also be investigating the impacts on the family when one of its members has mental illness. I am inviting you, as a family member, to take part in an interview. Data will be collected through semi-structured interviews, at a venue of your choice. The interview will be conducted in Maltese or English, as preferred by you, and it will last between one or two hours. The interview will be audio recorded and notes will also be taken during the interview. When the interview is finished, the results will be formulated in the form of a transcript.

While this experience may be of benefit to you and your relative with mental illness, there is no associated risk of harm lined with participation. Participation will be on a voluntary basis and it is reminded that you are free to withdraw from the study at any time and that the study is anonymous. A consent form will be signed prior to the beginning of the interview. All gathered information will remain confidential. Collected data will be kept in a safe place and will be destroyed at the end of the study. This information letter is being sent to you either via
Richmond Foundation or the Mental Health Association Malta and St. Jeanne Antide Foundation.
Should you be interested in participating in this research study, you are kindly requested to fill in the acceptance form attached and send it in the self-addressed envelope provided with this letter.

If you have any questions, please do not hesitate to contact me on 79200993 or racheal.galea.08@um.edu.mt or my supervisor, Dr Anne-Marie Callus, on 23403689 or anne-marie.callus@um.edu.mt.

Thank you for your time and I look forward to meeting you.

Yours sincerely,

Racheal Galea (researcher)
‘THE LIVED EXPERIENCES OF PEOPLE WITH MENTAL ILLNESS AND THE IMPACT ON THEIR FAMILIES’ CONSENT FORM TO FAMILIES WHO HAVE A FAMILY MEMBER WITH MENTAL ILLNESS (ENGLISH VERSION)

As a relative of a person with mental illness, I would like to participate in the research entitled “The lived experiences of people with mental illness and the impact on their families”.

I am aware that:
• Information will be kept confidential
• The interview will be audio-recorded
• I can choose not to answer certain questions
• I can withdraw his/her consent at any time
• All personal information will be kept confidential
• All recordings and transcripts will be destroyed after the end of the research.

Name & Surname  __________________________________________

Signature   ____________________________________________

Date   _________________________________________________

Signature of Researcher  ____________________________________________
APPENDIX 2B – INFORMATION LETTER AND CONSENT FORM FOR RELATIVES OF PEOPLE WITH MENTAL ILLNESS (MALTESE VERSION)

8 ta' Jannar, 2016

Ghaziz/a partecipant/a,

Ittra ta’ Stedina (Verzjoni bil-Malti)

Jiena qieghda nsegwi kors f’livell ta’ Masters fl-Istudju dwar id-Dizabilita’ fl-Universita ta’ Malta. Bhala parti mill-kors imsemmi, jien se naghmel studju msemmi “The lived experience of people with mental illness and the impact on their families”. L-istudju se jsehh bejn Mejju 2016 u April 2017.


Jekk inti interessat/a li tiehu sehem f’din ir-ricerka, inti mitlub/a timla l-formola ta’ approvazzjoni ta’ hawn that u tibghatha fl-envelopp provdut ma’ din l-ittra.

Jekk ghandek xi mistoqsijiet, jekk joghgbok tiddeijaqx tikkuntattjani fuq in- numru 79200993 jew racheal.galea.08@um.edu.mt jew lis- supervizur, Dr Anne-Marie Callus, fuq 23403689 jew anne-marie.callus@um.edu.mt

Grazzi tal-hin tieghek u nistenna minghandek.

Dejjem tieghek,

Racheal Galea (ricerkatur)
‘THE LIVED EXPERIENCES OF PEOPLE WITH MENTAL ILLNESS AND THE IMPACT ON THEIR FAMILIES’ FORMOLA TA’ KUNSENS LILL- FAMILJI LI GHANDHOM MEMBERU TAL- FAMILJA B’ MARD MENTALI (VERZJONI BIL- MALTI)

Jiena, bhala familjar ta’ persuna b’ mard mentali, nixtieq nippartecipa fl-istudju msemmi “The lived experiences of people with mental illness and the impact on their families”.

L-informazzjoni ta’ l- istudju ser tinzamm b’mod kunfidenzjali
Il- partecipant/a j/taccetta’ li tigi rrekordjat/a
Il- partecipant/a j/tista’ jaghzel li ma jwegibx ghal certu mistoqsijiet
Il- partecipant/a j/tista’ j/tirtira’ mir-ricerka fi kwalunkwe hin

Isem u Kunjom

Firma

Data

Firma tar- ricerkatur
APPENDIX 3A – INFORMATION LETTER FOR NON-GOVERNMENTAL ORGANISATIONS (ENGLISH VERSION)

8th January 2016

Dear Sir/Madam,

I am currently reading for a Masters Degree in Disability Studies within the University of Malta. As part-fulfilment of the requirements of the above-mentioned course, I am carrying out a research project entitled “The lived experiences of people with mental illness and the impact on their families”. The study will take place between May 2016 and April 2017.

The study aims to explore the lived experience and perspectives of people with mental illness and the barriers that they are faced with, in society. It will also be investigating the impacts on the family when one of its members has mental illness. Data will be collected through semi-structured interviews, with the participants at a venue of their choice. The interview will be conducted in Maltese or English, as preferred by the individual, and it will last between one or two hours. Each participant will be notified that the interview will be audio recorded. Notes will also be taken during the interview. When the interview is finished, the results will be formulated in the form of a transcript.

While this experience may be beneficial to the participant, there is no associated risk of harm lined with participation. Participation will be on a voluntary basis and the participants are reminded that they are free not to answer any particular questions or to withdraw from the study at any time. A consent form will be signed prior to the beginning of the interview. All gathered information will remain confidential. The real names and any identifying personal details will not be used in the research. Collected data will be kept in a safe place and will be destroyed at the end of the study.

As I will be involving people with mental illness and their families in my study, I would appreciate receiving your permission to invite service-users from your organisation and their families to participate in my research.
If you have any questions, please do not hesitate to contact me on 79200993 or racheal.galea.08@um.edu.mt or my supervisor, Dr Anne-Marie Callus, on 23403689 or anne-marie.callus@um.edu.mt.

I thank you very much in advance.

Yours sincerely,

Racheal Galea (researcher)
APPENDIX 3B – INFORMATION LETTER FOR NON-GOVERNMENTAL ORGANISATIONS (MALTESE VERSION)

8th January 2016

Ghaziz Sinjur/a,

Bhala parti mill-kors Masters fl-istudju dwar id- Disabilita, jien se naghmel studju msemmi “The lived experience of people with mental illness and the impact on their families”. L-istudju se jsehh bejn Mejju 2016 u April 2017.


Billi ser jintuzaw persuni b’mard mentali u l- familji taghhom, napprezza li nircievi l-permess tieghek biex inkun nista’ nuza’ partecipanti, bil- kunsens taghhom, mill-organizzazzjoni taghkom.

Jekk ghandek xi mistoqsijiet, jekk joghgbok tiddeijjaqx tikkuntattjani fuq in- numru 79200993 jew racheal.galea.08@um.edu.mt jew lis- supervizur, Dr Anne-Marie Callus, fuq 23403689 jew anne-marie.callus@um.edu.mt
Nixtieq nirringrazzjak bil-quddiem.

Dejjem tieghek,

Racheal Galea (ricerkatur)
APPENDIX 4A – INTERVIEW QUESTIONS FOR PEOPLE WITH MENTAL ILLNESS (ENGLISH VERSION)

- How is your relationship to other members of the family? (i.e. parent, partner, sibling, child or other)

- How long have you had the mental illness?

- What was your reaction when you were told that you have a mental illness?
  ✓ Did you have any support?
  ✓ Did you seek any support?

- Did you seek for information about the illness?
  ✓ If yes, did you cope more effectively with it?
  ✓ If not, why not?
  ✓ Do you intend to seek for (further) information?

- Has the presence of mental illness affected your daily routines?

- Has the presence of mental illness affected the financial situation?

- Has the presence of mental illness affected your own health and your own mental well-being?

- Has the presence of mental illness affected any other aspect of your life?
  ✓ Positive or negative experiences

- Do you feel that people treat you differently when knowing that you have a mental illness?
  ✓ Positive or negative experience
• Do you have support?
  ✓ Any associations
  ✓ Support groups
  ✓ Family and friends

• How would you describe the mental health services?
  ✓ In the medical field
  ✓ In the social field

• From your experience, does the family help you in the recovery process?

• How do you think you are perceived by society in general?
  ✓ Positive or negative perceptions
  ✓ General public
  ✓ Employers
  ✓ The media

• Do you feel that these perceptions affect you in any way?

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<th>Main question</th>
<th>Prompts</th>
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APPENDIX 4B – INTERVIEW QUESTIONS FOR PEOPLE WITH MENTAL ILLNESS (MALTESE VERSION)

- X’ inhi - relazzjoni tiegħek mall- koplament tal- familja tiegħek? (genitur, sieheb/siehba, huk/ohtok, wild, ohrajn)

- Kemm ilek tbati mil- mard mentali?

- X’ kienet ir- reazzjoni tiegħek meta l-professjoni medika qallek li ghandek marda mentali?
  ✓ Kellek xi appogg?
  ✓ Fittixt appogg?

- Fittixt xi informazzjoni fuq il- mard mentali?
  ✓ Jekk iva, ikkoperajt ahjar mal- marda?
  ✓ Jekk le, ghalfa jr?
  ✓ Ghandek hsieb li tfittex informazzjoni?
  ✓ Il- midja taffettwak?

- Il- prezenza tal- mard mentali affettwatlek ir- rutina ta’ kuljum?

- Il- prezenza tal- mard mentali affettwatlek is- sitwazzjoni finanzjarja?

- Il- prezenza tal- mard mentali affettwatlek is- sahha tiegħek u s- sahha mentali tiegħek?

- Il- prezenza tal- mard mentali affettwatlek xi aspetti ohra tal- hajja?
  ✓ Esperjenza posittiva jew negattiva

- Tahseb li n- nies jittrattawk differenti meta jafu li ghandek mard mentali?
  ✓ Esperjenza posittiva jew negattiva

- Ghandek xi tip ta’ appogg?
• Kif tiddeskrivi s- servizzi tas- sahha mentali?
  ✓ Fil- qasam mediku
  ✓ Fil- qasam socjali

• Mill- esperjenza tieghek, tahseb li l- familja tieghek tghinek fil- process ta’ irkuprar?

• Kif tahseb li n-nies b'mard mentali huma perċepiti mis-soċjetà b'mod ġenerali?
  ✓ Perspettivi posittivi jew negattivi
  ✓ Il- pubbliku generali
  ✓ Min ihaddem
  ✓ Il- midja

• Thoss li dawn il-perċezzjonijiet jaffettwaw b’ xi mod?

| Mistoqsijiet | ✓ ‘Prompts’ |
APPENDIX 5A – INTERVIEW QUESTIONS FOR FAMILY MEMBERS OF PEOPLE WITH MENTAL ILLNESS (ENGLISH VERSION)

• What is your relationship to your relative with mental illness? (ie parent, partner, sibling, child or other)

• How long has your relative had a mental illness?

• What was your reaction when you were told that your relative has a mental illness?
  ✓ Did you have any support?
  ✓ Did you seek any support?

• Did you seek for information about the illness?
  ✓ If yes, did you cope more effectively with it?
  ✓ If not, why not?
  ✓ Do you intend to seek for (further) information?

• Has the presence of mental illness in the family affected your daily routines?

• Has the presence of mental illness in the family affected the financial situation?

• Has the presence of mental illness in the family affected your own health and your own mental well-being?

• Has the presence of mental illness in the family affected any other aspect of your life?
  ✓ Positive or negative experiences

• Do you feel that people treat you differently when knowing that you have a family member with mental illness?
  ✓ Positive or negative experience
• Do you have support?
  ✓ Any associations
  ✓ Support groups
  ✓ Family and friends

• How would you describe the mental health services?
  ✓ In the medical field
  ✓ In the social field

• From your experience, do families help in the recovery process of a person with mental illness?

• How do you think that people with mental illness are perceived by society in general?
  ✓ Positive or negative perceptions
  ✓ General public
  ✓ Employers
  ✓ The media

• Do you feel that these perceptions affect you in any way?
APPENDIX 5B – INTERVIEW QUESTIONS FOR FAMILY MEMBERS OF PEOPLE WITH MENTAL ILLNESS (MALTESE VERSION)

- X’ inhi r- relazzjoni tieghek mall- membru tal- familja li jbat/tbat minn mard mentali? (genitur, sieheb/siehba, huk/ohtok, wild, ohrajn)

- Kemm ilu l- qarib tieghek ibati bil- mard mentali?

- X’ kienet ir- reazzjoni tieghek meta l-professjoni medika qallek li l-qarib/a tieghek ghandu/ghandha marda mentali?
  ✓ Kellek xi appogg?
  ✓ Fittixt appogg?

- Fittixt xi informazzjoni fuq il- mard mentali?
  ✓ Jekk iva, ikkoperaqt ahjar mal- marda?
  ✓ Jekk le, ghalfejn? Ghandek hsieb li tfittex informazzjoni?
  ✓ Il- midja taffettwak?

- Il- prezenza ta’ mard mentali fil- familja affettwat ir- rutina ta’ kuljum?

- Il- prezenza ta’ mard mentali fil- familja affettwat is- sitwazzjoni finanzjarja?

- Il- prezenza ta’ mard mentali fil- familja affettwat is- sahha tieghek u s- sahha mentali tieghek?

- Il- prezenza ta’ mard mentali fil- familja affettwat xi aspetti ohra tal- hajja?
  ✓ Esperjenza posittiva jew negattiva

- Tahseb li n- nies jittrattawk differenti meta jafu li ghandek membru tal-familja b’ mard mentali?
  ✓ Esperjenza posittiva jew negattiva

- Ghandek xi tip ta’ appogg?
  ✓ Assocjazzjonijiet
✓ Gruppi ta’ appogg
✓ Familja u hbieb

• Kif tiddeskriivi s- servizzi tas- sahha mentali?
✓ Fil- qasam mediku
✓ Fil- qasam socjali

• Mill- esperjenza tieghek, tahseb li l- familji jghinu fil- process ta’ ċirkuprar ta’ persuna b’ mard mentali?

• Kif tahseb li n-nies b’mard mentali huma perċepiti mis-soċjetà b’mod ġenerali?
✓ Persptivvi posittivi jew negattivi
✓ Il- pubbliku generali
✓ Min ihaddem
✓ Il- midja

Thoss li dawn il-perċezzjonijiet jaffettwawk b’ xi mod?

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