Bachelor Thesis

The Legacy for Adulthood of Parental Mental Illness

An anthropological exploration of the life-stories of adult children who grew up with a parent with mental health difficulties in Spain, as a call to increase visibility and support for this collective.

Gema Benavides Jimenez

Student Number: 6665691

Spring 2022

Wordcount: 14598

Supervisor: Amisah Bakuri

Abstract

The repercussions of growing up with a parent with mental health difficulties have largely been underexplored in available academic literature. Therefore, this research paper aims to highlight how once mental health problems erupt within the family, the impact is not only felt by the patient but also by their intimate others. Through a literature review and seven intensive interviews, this thesis explores the adult legacy of having a parent with mental health difficulties in Spain. Results show that the repercussions of having a parent with mental health difficulties are often difficult to label as either good or bad but are rather situated in a spectrum. For example, while having an increased independence and sense of maturity was often reported as a source of pride, there is also the risk of taking too many responsibilities on their shoulders. However, despite having difficulties, drawing boundaries and negotiating responsibilities, participants also recognized that despite the challenges they have faced as they learned how to live with parental mental illness, they all have managed to get something good/useful out of it. Beyond the subjective impact that growing up with a mentally ill parent has had on my participants, this thesis also aimed to portray these individuals as experts through experiences, so my results also contain some of their criticism towards the health- care system, suggestions for improvement and general recommendations for other individuals living with a mentally ill parent.

Table of Content

Acknowledgement

Introduction

Mental health difficulties are not only lived by individual sufferers but also by their intimate others (Gammerltoft & Oosterhoff, 2018). Worldwide, 15-23% of children live with a parent with a mental illness (Leijdesdorff et al., 2017). However, often the profound impact that parental mental illness has on the lives of their children has gone largely unrecognized. This is mainly a result of the general tendency of mental health professionals and services to treat mental illness by narrowly focusing on the directly affected individual. However, mental illness in the family is a fuss that sweeps up everyone (Dickens & Marsh, 1994).

The full impact of parental mental health difficulties may only become apparent much later, years or decades after their initial encounter with mental illness. Therefore, the failure to recognize and address the impact of mental illness on family members can have devastating and persistent long-term effects, including the introduction of secondary trauma (Dickens & Marsh, 1994).

Being myself the daughter of a mother who struggles with mental health difficulties, I reckon the lack of support available for children who like me, grew up under the shadows of their parent's mental health difficulty. Given that the numbers of people suffering from mental health difficulties keep rising (The European Mental Health Action Plan 2013–2020), I think it is crucial to look beyond the impact that mental health difficulties have on the first-hand sufferers alone and also start focusing on those around them as well. In this case, on their children.

Quantitative studies are useful to identify and develop preventive interventions in children of mentally ill parents to decrease their risk of developing any psychopathology in the future. Therefore, many of the already existing studies on the effects of parental

mental illness focus on the prevalence of psychopathology and risk- management (Leijdesdorff et al., 2017). However, these children are more than mere statistics representing a high- risk population for psychopathology (Leijdesforff et al., 2017). Hence, there has been a call for more qualitative approaches to the topic (Gladstone et al., 2011), to explore the subjective lived experiences of these children to be able to better understand how childhood experiences and familial relationships can impact the longer-term health/ social status of the child into adulthood. So, rather than merely planting the seeds for panic with risk-assessment studies, researchers should also focus on listening carefully to the stories of these individuals so we are better able to attend to their needs and figure out how we can support them best.

Consequently, it is my aim in this research project to explore more in depth the experiences of Spanish adult children of parents with mental health difficulties. Given inadequate studies that explore the influence that socio-cultural, economic, and political factors have on shaping the experiences of children with parental mental health difficulties, I decided to focus on Spain – which traditionally have been characterized by strong family loyalties that have sustained inter-generational micro-solidarities (Moreno & Marí-Klose, 2013), to see whether and how cultural values affect the experiences of parental mental illness. Moreover, given that I am Spanish myself I believe that conducting interviews in my own native language allows me to connect and relate deeper with my participants.

The guiding research questions for this thesis is: *What is the legacy for adulthood of having a parent with mental health difficulties in Spain?*

My main objective is to explore on the one side how these adult children think about how their parent's mental health difficulties have shaped who they are and the repercussions these experiences have had and/or have on their wellbeing and the person

they have grown into. On the other side, I seek to situate the participants' experiences in the larger social -cultural context of Spain. Therefore, while this work tries to highlight the impact of having a parent with mental health illness, to understand this, I also considered important to explore how the influence that the socio-cultural and political-economic context in which the individuals are situated, shape their subjective experiences with parental mental illness.

Originally, I decided to use the term mental health difficulty instead of using terms such as "problem" and/or "illness", to avoid the need to rely on diagnostic terminology to determine inclusion. However, all my participants reported having their troubled parent being officially diagnosed by a psychiatrist under the Diagnostic and Statistical Manual of Mental Disorders V (DSM -V) criteria, and they all used the terms "problems" and "illness" interchangeably to talk about their parents' difficulties. So, in the end I decided as well to use those terms throughout my paper.

Right after this introduction, the first two chapters of my thesis will thoroughly explain the methodology and theoretical framework I used for this research. The third chapter will review the research on the experiences of being the children of a parent with mental health difficulties. Additionally, welfare arrangements, health care system and family values in Spain will also be developed in more detail in chapter three. With the purpose of providing enough context to situate my participants' experiences. Then, in chapters four to eight I present my findings. Chapters four and five focus on the personal legacies of having a parent with mental health difficulties. Chapters six to eight focus on my participants perspectives on what could be improved and recommendations for other's undergoing similar struggles. Lastly, in chapter nine I will discuss my findings under the light of my theoretical framework, and I will finally conclude based on my findings and the already reviewed literature, as well as by briefly reflecting on my positionality.

Chapter 1: Methodology

1.1. Methods

This research is based on secondary data by reviewing available literature in the field of mental health and medical anthropology. This was complemented by seven in-depth intensive interviews. In this section of my thesis, I will carefully explain my methodology while I also reflect on the choices I made.

1.1.1. Literature research

To get myself familiarized with how the subject was being dealt with on the literature – and whether it was even been dealt with in the first place, and if so, to get a picture of the larger academic debates taking place, and to explore which terminology was being used to talk about the subject matter, I initiated this project by first undertaking some pre-liminary literature research using searching engines such as "Google Scholar" and "WorldCat". I also searched through specific academic journals such as the "Journal of Social Worker in Mental Health" and the "Medical Anthropology Journal." However, I was very frustrated with the lack of qualitative literature addressing the experiences of children with parental mental health difficulties and/or scientific research conducted in Spain on mental health.

Nevertheless, I found a couple of studies in the form of meta-analyses and/or review papers that highlighted the most common themes present in adult children retrospective accounts of the effects of having a parent with mental illness. Additionally, I also found a book on the experiences of being the children or the sibling of a person with mental health illnesses. These all helped me to develop a list of themes to structure my interview guide.

1.1.2. Intensive Interviews

The main method used to gather data for this research were intensive interviews. Since I wanted to give my participants' voices the center stage on my research, I decided to employ this technique of interviewing as it allows the researchers to collect data constituted by an in depth-exploration of the participant's experiences (Charmaz, 2014). This interviewing method is mostly focused on how participants experience specific events and allow them the freedom to frame it in their own way and emphasize on what they view as more relevant (Charmaz, 2014). Therefore, when conducting the interviews, I had a few pointers that would guide me towards certain discussion points. However, I tried to keep the conversation quite open to give the participants as much freedom as possible in deciding the direction in which the interview would flow towards.

Overall, I conducted seven interviews, lasting between fifty minutes to an hour and half each. Given time and mobility constraints, six out of seven interviews were conducted online, except for one which was possible to conduct in person. For the other six interviews, video-calls were used to minimize the chance of missing out on important non-verbal cues that might had been easier to grasp on during an in-person interview than via phone call. All interviews were tape-recorded with their previous consent and later transcribed verbatim. Lastly, given that the interviews were conducted in Spanish, I coded and translated the most relevant quotes and pieces into English, in order to include these in my written report. However, I acknowledge that some words in Spanish carry particular connotations that might be hard to convey once these are literally translated into English.

The approach that I employed throughout this project was highly open and flexible, as I tried to keep preconceived expectations to the minimum and remained open to exploring new avenues as they presented themselves, to be able to adapt to what my

participants wished to emphasize through their storytelling. I believe that as a result of this process I was able to learn much more about myself and the phenomena studied than I would have otherwise. Not to say that this approach was easy, as I encountered challenges along the way some which involved the reliving of traumatic experiences. Indeed, I felt overwhelmed at times, and I considered whether I was ready to embark on this journey and to question what my end goal was with this project. Thankfully, I was able to realize that by already creating the space for these types of stories to be listened to, this was already a steppingstone.

I believe that by participating in this study, adult children of parents suffering with mental health difficulties are gaining insight into their own experiences. In fact, one of my biggest hopes for this project is that it can serve as a tool for self-reflection for those I interview as well as for myself, as I explore how others frame their own experiences with parental mental health difficulties. Additionally, I hope that by having their voices uplifted and by sharing their wisdom with a wider audience of readers – some who might also be struggling with similar circumstances, they will feel empowered and help to remind themselves and others that they are not alone.

1.2. Population and recruitment method

The aim of this paper is to investigate the adult legacy of having a parent with mental health difficulties in Spain. Therefore, my participants had to meet the following criteria: 1) they all must be Spanish and share/have grown up under the influence of the Spanish culture, 2) they must be over 18 years old, and most importantly, 3) have a parent suffering from mental health difficulties. My sample was composed of seven females with an age range between 19 and 36. The participants came from different provinces within

Andalucia, Spain; four from Almeria, one from Cordoba and one from Granada. Lastly, one participant came from Barcelona but was living in Utrecht.

Six out of seven of my interviewees have a mum suffering from a mental health difficulty, and only one of my interviewees had a dad suffering from a mental health difficulty and who had died three years ago already. Five of my interviewees' parents suffered from some form of schizotypal psychopathology, with most of them having suffered, or currently suffering from an episode of major depression. Three of my interviewees' parents suffered from mood disorders and one of my interviewee's parents had suffered from Huntington Chorea Syndrome. Only one of my participant's parents was described in the interviewee's own words as being "cured". However, all the other participant's parents were still currently suffering from a mental health difficulty, with one still been interned in a psychiatric hospital at the time of the interview. For the most part, the women interviewed lived with their mentally ill parent, except for the cases in which the parent have already passed away, were interned in a psychiatric hospital, or the interviewees themselves were studying somewhere else.

Recruitment took place online. First, I reached out to mental health organizations in Spain which could facilitate the access to this pool of participants. However, this proved to be a very slow process. So, after being put in contact with some people through one of the organizations, I mainly relied on a snowball sampling method in which from word of mouth of my interviewees and friends, I was able to find new participants. Additionally, I also used social media platforms such as Instagram to spread the word through my personal network of contacts. This recruitment method proved to be effective given the overwhelmingly positive response of my contacts who were messaging me for more information and who were sharing my "post" on their own personal accounts. This allowed me to reach out to a larger and more diverse pool of people. However, it is worth

mentioning that most of mine and my friends' following are young adults between the ages of 19 to 26 years old, so reaching out to older generations might not be as effective through this sampling method.

1.3. Ethics

Through the process of conducting my research I was aware that the relationship and interaction between researcher and participant can often provide ethical challenges (Sanjari et al., 2014). Hence, it was my responsibility as the researchers to be aware of these complex dynamics to be able to conduct safe and ethical research. Particularly, given the deeply personal and sensitive topics that were of interest for this research. So, taking into consideration the sensitivity of the topics discussed was a priority in terms of how these were approached. In fact, as a researcher I hold the responsibility of considering and minimizing the negative impact of re-living traumatic experiences on the research participant (Morgan & Björkert, 2006), and/ or of disclosing deeply personal information, which perhaps in some cases might have not even been verbalized ever before, or only with very close circle of people.

To ensure the anonymity of the participants I used pseudonyms to refer to my research participants instead of using their real names. Additionally, to deal with the ethical issue of consent, participants were briefed on the nature and purpose of my research as well as on the sensitivity of the subject matter when they were first contacted to participate, to make sure that they make an informed decision of whether to participate or not (Boeije, 2010). This process was formalized by signing a consent form which they shared with me prior to the interview.

Additionally, I must acknowledge the ethical issue of trust as it can hold a complex position in the interaction between the researcher and the participants (Boeije, 2010). I

was aware than once trust has been established between the two parties, the participant is at the risk of entering a "telling mode", in which they share more information than what in reality they would feel comfortable sharing with me. Hence, as the researcher I had to bear with the responsibility to prevent this from happening and the possibility of exploitation of the research participant, by asking them whether they felt comfortable with everything that had been shared and if there was anything they would like me to remove/add from the final research report (Boeije, 2010).

Moreover, to preserve the issue of sensitivity at the forefront throughout the interview process, I reminded the participant of their right to withdraw from the interview at any point if it gets too hard, and/or decide to not answer questions with which they do not feel comfortable with. However, my responsibility as a researcher stretches beyond the interview stage. For me it was also particularly important to attend to the aftermath of the re-living of the participants' painful, traumatic and/ or personal experiences, since these can become more distressing after our initial conversation, hence the importance of aftercare (Sanjari et al., 2014). Thus, how I dealt with this issue was by facilitating a reflective discussion session post interview in which participants were debriefed and encouraged to reflect on how this conversation had made them feel.

Yet, despite some of the above-mentioned potential risks of participation, I think that overall participants benefited from having the opportunity of sharing their stories as it might have helped them to create a space that reflects their lived experiences more accurately. In addition, as I hope to be able to share my findings with people from organizations in a position to initiate change at the institutional level, I believe they may benefit from having their voices heard.

1.4. Positionality

As mentioned earlier in the introduction, given that I am myself the daughter of a parent with mental health difficulties, it is vital for me as the researcher to acknowledge my positionality. Thus, to understand how my personal background and lived experiences not only influence how I analyze the data, but also how I understand and interpret myself the stories I am being told by my interviewees. As the project unfolded, I realized that as the researcher, having lived a similar experience to that of my interviewees with parental mental health difficulties proves to be both, a strength, and a weakness. While it makes my passion and engagement with the topic significantly stronger, as well as it enhances my ability to connect with other participants and to be able to empathize and generate an atmosphere of trust and comfort, my own personal experiences might also bias how I interpret and evaluate results, as well as how I guide conversations towards certain topics more than others. Additionally, while we all share to a certain extent comparable stories, I must recognize that our experiences are not all the same, based on other factors such as socio-economic background, religion, gender, etcetera. Specially, because all the aforementioned factors do in fact largely shape how we each frame our lived experiences, how we make sense of them and how we tell them (Hesse-Biber & Piatelli, 2007).

Thus, in line with what I just mentioned, I think that gender and age were the two most prominent aspects of my identity beyond my shared experience with parental mental health illness, that might have influenced this research. Given that all my participants, including myself identified as women, this might have allowed both parties to feel more comfortable being vulnerable and opening up to a stranger. Additionally, given that all my participants were young adults, in most cases there was not an excessively big generational gap, which enabled for a better understanding of the contextual setting and

socio-economic and political landscape in which the events described during the interviews were taking place.

To mitigate the effects of my own positionality when conducting this research, I made use of a fieldwork notebook, to engage in a reflexive process throughout the entirety of the research. In this notebook I took descriptive and analytical notes as well as methodological ones, where I reflected on how certain things triggered me – such as the way some participants recalled difficult experiences that I have experienced myself as well, or how they expressed feeling about certain events, as I had also felt similarly before – and how such triggers might have influenced how I approached and analyzed certain instances.

1.5. Challenges facing the researcher

While I was not the direct subject of study for this research, given my personal lived experience of parental mental health difficulties, I was undertaking research that certainly bridged to an extend the subject-object divide. While I was aware of the tremendously life enhancing and capacity building that such works can carry, transformation and growth are not easy processes (Hooks, 1994). Hence, for me to see these processes I have to be patient and committed to undergo the journey no matter how difficult it gets.

Consequently, it is important for me to acknowledge that there were certain challenges involved for me as the researcher conducting this research. In particular, I found certain aspects of the process emotionally difficult, with the interview transcribing process being the most challenging one for me. However, seeking the support of friends, my partner, my tutor and my counsellor really helped me to be able to endure the journey and to have the opportunity to work through many of the issues that I was personally confronted with

as I went through the research process. Despite the risks associated with re-living trauma and hidden emotions and scars – which I certainly did experience sometimes, I feel that hearing the stories of others who like myself also share a story of parental mental health difficulties, was a very validating and self-assuring experience. Yet, despite being far from giving me any sort of closure, this pushes me forward in my healing journey and in my process of self-understanding and developing more self-compassion.

1.6. Pitfalls of the methodology

I recognize that as with any research process, regardless of how much you try to minimize them, there are always some pitfalls of the methodology. In the first place, the fact that I had to conduct most of my interviews online might make the interview process feel a bit less personal and uncomfortable for the participants to open up. Yet, the ability to conduct an interview from the safety of the participants' own homes, could have also had the opposite effect on the participants. Hence, they might have felt even more comfortable when talking about sensitive issues. However, if there is something that online interviewing proved to be harder than expected was to adequately respond to the emotional reactions of my participants. Particularly, when a participant cried during one of the interviews. This felt difficult and at times uncomfortable to show emotional empathy and support through a screen, as one could not soothe them with any form of physical touch. However, I do believe that in the end I managed to work myself around it.

Second, I reckon my sampling method as another limitation of my research since I depended heavily on snowballing and all participants were female. Hence future research should also strive to include participants who identify with other genders, to see

whether they report similar experiences and further analyze the impact of gender on shaping these experiences.

Lastly, I found the time frame given to develop this project, of around four months, quite limiting. Thus, I saw myself constrained to the possibility of conducting just seven interviews and to explore only a couple of themes out of all other possible ones. Even though my seven interviews allowed me to compel enough information and to narrow down my research focus, I hope to be able to further dig into other questions and issues that arouse during my interviews in another research project.

Chapter 2: Theoretical Framework

2.1. Mental Illness in the Domestic World

Gammeltof and Oosterhoff (2018) used the term "Domestic Worlds" to refer to both families and households. In this thesis, family is understood in terms of nuclear family. There are only few ethnographical works that have looked at the effects of mental illness on the domestic worlds of patients (Gammeltof & Oosterhoff, 2018; Snell- Rood et al, 2018; Jenkins, 2015). Despite the tendency to isolate the effects of mental health illness to individual sufferers; partly due to the dominance of biomedical explanations focused on symptom solving and mechanistic explanations of brain functioning, in this thesis I want to highlight the intersubjective nature of mental health conditions, demonstrating how "individual" mental states are inseparable from the states of mind of their intimate others, as family members absorb and share distress with the mentally ill individual (Gammeltof & Oosterhoff, 2018; Snell- Rood et al, 2018). By particularly focusing on how mental illness affects the offspring of patients in Spain, I aim to build on previous work in anthropology that has investigated how intimate others are often intensely involved when an individual suffers psychological problems.

Gammeltof and Oosterhoff (2018) also suggested to treat these units; the domestic world, "as open structures that are fundamentally shaped by social and political economies"(1). In other words, societal conditions such as constrained access to health care, political and economic policies and dominant cultural values, often are filtered through the socio-moral dynamics that characterize families and households. For example, ethnographic work has shown how cutbacks in state health and social-benefits provision reduce both, the support for those suffering from mental health problems and leaves families with the task of providing social protection and economic care for

vulnerable individuals (Snell- Rood et al., 2018). Therefore, the given framework helped me to explore how the particular socio-cultural context of Spain shapes the impact that growing up with parental mental illness have on the individuals I interviewed.

2.1.1. Kinship

In my work I was also largely inspired by Sahlins (2011) definition of kinship as a "mutuality of being." I believe this notion further helps me to illustrate how mental illness is "co-experienced" by parents and children.

2.1.2. Kinship Ethics

The overly reliance on the domestic world as a source for protection and care of the mentally ill also reflects the moral expectations for family members, particularly women. Thus, similarly to the authors Snell-Roods et al (2018), throughout my thesis I place a large emphasis on "kinship ethics" – the cultural and moral expectations for the family to provide care and a safety net for relatives struggling with mental health – to comprehend mental health experiences in the domestic world.

2.2.The legacy of parental mental illness

The authors Marsh and Dickens (1994) use the term "legacies" to refer to how ongoing experiences in adulthood could be shaped by early experiences with one's family. Under this framework, the authors explore how one's experiences with parental mental illness may have shaped one's personal, occupational, interpersonal, and family legacies. Within this thesis I found using the term legacy very useful to explore how the children of parents with mental health difficulties understand how this experience has shaped the person they have become and their wellbeing. Hence, I decided to borrow the term legacies for my own research question.

2.2.1. Personal Legacy

Marsh and Dickens (1994) discussed several legacies such as personal, interpersonal, occupational, and family. However, in this thesis I only focus on the personal legacy because it considers how people's early experiences shaped their identity and self-esteem and/or their need for perfectionism and control. Moreover, under personal legacy, the authors claim that people should explore their own mental health circumstances not in the sense of symptomatology but more to do with their experiences of subjective burden. So, in my own research I explore personal legacy by asking my interviewees questions about how they think that their parent's mental illness have impacted their own wellbeing, including how it has shaped their identity and the development of certain personality traits and their role within their families.

Chapter 3: Literature Review

3.1. Children of parents with mental health difficulties

Research on children of parents experiencing mental health difficulties is scarce with most of it published in nursing, psychology, and social work journals. In the literature we find that the most common source of information on the experiences of having a parent with mental illness comes from retrospective reports of adult children, where adult children are asked to recall specific instances of their childhood (Nicholson et al., 2001). These people often describe negative consequences from their experiences with parental mental illness, such as the feeling of anger, isolation, shame, fear, sadness, chaos, grief, neglect, feelings of hopelessness, frustration and confusion, identity problems, poor self-esteem and trust and intimacy difficulties (Nicholson et al., 2001). Also, many mention living through very difficult situations partly because of stigma surrounding mental illness and the lack of family discussion and/ or education. However, some accounts also report acquiring positive characteristics such as strength, empathy, compassion, tolerance, and the appreciation of life among others; all of which reflect the development of resilience in the face of family difficulties (Wepf et al., 2021).

Additionally, in previous research, most study participants have usually come from the United States of America or other Anglo-Saxon countries and have been adult children of women with serious mental illness, mostly diagnosed with psychosis, schizophrenia and/or described as having a chronic or severe mental illness (Nicholson, 2001)

Besides a handful of scholarly papers written for academic journals, there are two other main bodies of work on the experiences of the children (and siblings) of the mentally ill, both books written by the same authors Diene Marsh and Rex Dickens. For this paper

I will review the main findings from their first book "*Anguished Voices: Siblings and adult children of persons with psychiatric disabilities*" (1994), which is an edited volume of personal accounts of adult children and siblings of a mentally ill family member. This book particularly helped me to develop a set of themes I was interested in further exploring throughout my thesis. This book also provided me with a guiding framework to approach the conversation from an academic perspective. In the following section I will summarize the most relevant findings for my research.

3.1.1. "Anguished Voices: Siblings and adult children of persons with psychiatric disabilities"

The authors of "*Anguished Voices*" assert that the implications of having/ growing up with a parent suffering from mental health difficulties are often pervasive, yet one is frequently unaware of the ways one has been impacted. The authors explain that growing up with an ill parent places a child or adolescent at increased risk of distress and impairment. Children are more vulnerable than adults to stressors in their environment because they have fewer coping skills and strategies for dealing with threatening circumstances and therefore, they are more easily overwhelmed by those circumstances. In fact, a later study by Murphy et al (2010), further argued that one of the reasons why children seem to be more vulnerable to long-term negative repercussions of their parent's mental health illness, than other relatives or acquaintances is because children are more dependent on their parents for safety and care. However, given that a parent's mental illness can decrease their ability to provide these to their child, this circumstance can leave the child in a very unstable position.

The authors of "*Anguished Voices*" further state that when a family is facing acute crises these children within the family, face a few risks including obstacle to their own development, unhealthy family roles and relationship, as well as facing challenges in their

peer relationships. For example, children in such environments may be required to take on responsibilities that are not appropriate for their developmental phase. Namely, children may become parentified by assuming a care-taking role. As well, as adults if these children ever leave the family home to start their own life, it is not uncommon for them to feel guilty about leaving their parent behind.

"Anguished Voices" continues to report how these children continue to face challenges of their own into adulthood, largely triggered by their condition of having a parent with mental health difficulties. Among the issues raised were concerns about providing care for the distressed relative, and the challenges that come with an unpredictable and uncertain future. Moreover, they also expressed ongoing concerns with low-self-esteem, perfectionism, psychic numbing, and problems with trust and intimacy. They also identified intense feelings of loss and grief relating to their own experiences and that of their distressed family member, and many also expressed fears of developing symptoms of mental illness themselves. However, on a more positive note, the authors do point out that despite experiencing difficult situations, many people emerge much stronger from such experiences.

Under the light of the evidence of the collected testimonies, the book finishes by emphasizes that care and assistance need to involve entire families in the treatment and support process because, although it is an individual who receives the diagnosis, it is the entire family who often must respond to the distress as it manifest.

3.2. Welfare arrangements, health care system and family in Spain

3.2.1. Family values in Spain

In Spain there is a saying that goes: "The only truly poor person is one who has no family". Strong family loyalty and intergenerational solidarity are strong social norms

shared by the society as a whole and learned at very young ages (Reher, 1998 *in* Moreno & Marí- Klose, 2013). Inevitably, Spain is characterized by a strong sense of familism or family solidarity (León & Pavolini, 2014; Saraceno, 2016) – a cultural value referring to the importance of strong family loyalty , and a heavily existing care culture – in which it is normal that families take the responsibility of caring for people, often in ways beyond their capabilities and/or at expense of their own wellbeing (Guedes, Pereira & Chaves, 2017). The cultural and societal relevance of such believes and practices have no resemblance in other countries in Central and Northern Europe, where family ties tend to be weaker and the capacity of the family to function as a welfare provider is limited (Moreno & Marí-Klose, 2013).

3.2.2. Familialistic Systems of Welfare

The emphasis on solidarity, the acceptance of care responsibilities and the existence of strong family ties and support networks have significant implications on how social risks and needs are dealt with and, therefore, upon the structuring and functioning of welfare states (Moreno & Marí- Klose, 2013). The extent to which the caring function of the family is promoted determines whether a welfare regime is conceptualized as a familialistic or a de-familializing system. Within the "welfare triangle" of state, market and private households, caring responsibilities can be distributed in different ways. (Leitner, 2003). Spain, as many other Mediterranean countries is characterized by a familialistic welfare system in which the state explicitly attempt to strengthen social responsibility among family members (Leitner, 2003). As a result, the centrality of the family enables governments to rely on these to meet the caring needs of their members, thus keeping political demand for public assistance rather low (Moreno & Marí- Klose, 2013).

3.2.3. The de-institutionalisation and de-centralisation of mental health care in Spain

Many western European countries during the mid-20th century began to shift the locus of mental health care away from mental hospitals to community-based settings (Salisbury, Killaspy & King, 2016). In Spain, this process of deinstitutionalization started to be carried out from the 1980s under the name of "Psychiatric reform" (Vazque-Barquero & Garcia). Critiques of the de-institutionalization process claim that policy makers have sometimes seen de-institutionalization as an opportunity to cut health care costs and have been slow to redirect investment into the necessary community-based services that are required to help facilitate independent living (Salvador –Carulla et al., 2010).

In Spain, the process of deinstitutionalization was paired up with the decentralization of all health care responsibilities – including those for mental health, away from the national government to the 17 Autonomous Communities. As a result, there has been an increase in the diversity of health and social care service structures and the fragmentation of the decision- making structures. However, this process has not been accompanied by any parallel development of new national agencies or efficient coordination systems across autonomous community. Hence, one of the main problems facing the country is the coordination of health and social care services, as there are around 486 Community Mental Health Centers across the country. This challenge is aggravated by a complex range of governmental structures (regional, provincial, and local) which makes coordination largely inefficient; despite efforts in many Autonomous Communities to develop coordination commissions (Salvador-Carulla, Costa-Font, Cabases, McDaid & Alonso, 2010).

Overall, given the present familialistic regime of welfare, the deinstitutionalization and decentralization process of mental health care in Spain have

resulted in the underdevelopment and underfunding of public care policies and services specially in mental health compared to other healthcare services, that have led to the increased transfer of public health system responsibilities to the families (Marques & Navarro - Perez, 2019). In fact, 88% of the work and care towards the people suffering from mental health problems is carried by informal caretakers, such as parents, offspring, and friends (care4carers survey). All in all, the health care management model developed in Spain is based on containing costs, limiting professional intervention, and indirectly forcing the family to become more involved in looking after someone in a situation of dependence (Aiken et al., 2012).

Under the light of a strong family loyalty, unity, and solidarity along with the existing socio- political structures that reinforce and strengthen the role of the family in providing welfare, I am interested in exploring how these particular circumstances shape the adult legacy of having a parent with mental health difficulties in Spain.

Chapter 4: The long-term legacy of growing up with a mentally ill parent

Initially I went into my research hoping to find a clear cut between the positive and negative repercussions of having a parent with mental health difficulties. However, many of the effects I found were difficult to fit into a binary. For example, on the one hand, at first the ability to self-introspect and/or of being independent and more mature for one's age could be labelled as positive. Yet, on the other hand, when the ability to self-introspect turns into intense rumination and the latter into carrying too much responsibility on one's shoulder and feeling unsupported, these can turn into negative repercussions. Hence, it might turn to be more suitable to situate repercussions on a spectrum rather than into fixed categories.

Despite the ambivalent nature of most of the identified repercussions, participants did label some effects of growing up with a parent with mental health difficulties as particularly negative for their wellbeing. Many of my interviewees reported feeling at times overwhelmed by their circumstances, particularly when they found themselves with a lack of adequate support, either form their families, the larger health-care system, or both. Guilt and fear seemed to be the two most common emotions that arise as a result of having a parent with mental health difficulties and/or feeling responsible to some extent of their wellbeing and/or their care. These emotions while not always negative in nature, do seem to shape some of the life- choices, decisions and overall feelings of wellbeing and life-satisfaction of my participants. In other words, guilt and fear that arise from having a parent with a mental health condition seem to condition to a certain extend my participants thoughts and life, to quote Amanda: "*your life is being mentally limited, and often one is not even aware of it*".

4.1. Guilt: whose responsibility is it and should I be doing better and more?

Some of my participants mentioned their parent's situation triggering some form of guilt due to different reasons. Often this guilt is accompanied by mixed feelings about their role and responsibilities towards the ill parent. For example, Jimena mentioned how despite feeling like she should not have that responsibility or experiencing the burden (of looking after her mum), she does feel guilty if she does not do it and feels bad about it.

Amanda also mentions how she does not want to carry on her shoulders something for what she is not guilty for (her mum's illness), but still finds it hard to delineate between what her responsibilities as a daughter are versus what the social welfare system should help her out with. Hence, even though she fears that she is indeed taking too much on her shoulders she feels guilty if she does not do so, because who else would do it otherwise?

Maria also mentions how often she has felt guilty for thinking that she should be spending more time with her mum. She recognized that as a result of her engaging in more self-introspection and starting to talk more about the situation, that she has realized how guilty she feels for not spending more time with her mum or doing more for her. Yet, Maria feels guilty for having focused first on dealing with her own problems and thus not dedicating enough time to understand and deal with her mum's problems:

"I feel guilty about everything, for not being more attentive, for not looking up more information to understand her (Maria's mum) illness so that I know better what to do to help her (…) because when you have a parent like that, that is what you are supposed to do, but I recognize that I do not know as much as I should".

Overall, there seems to be a general theme of feeling like one is never doing enough, or that one can and should always do more – which often puts the individual in a quest to understand what their responsibilities as a daughter are and how to draw

boundaries – which will later be further discussed. Even though all participants seem to unconsciously recognize that they are not the reason and/or cure for their parent's situation, there seems to be a general feeling of insufficiency or perhaps frustration among them, for not being able to do more, and be better and more helpful for their ill parent or their families. This, I believe in fact can directly correlate to a lack of self-esteem, a need for external validation and/or a need for self-improvement – all of which, at least one was mentioned by each of my participants and which indeed, existing literature also seems to support (Murphy et al., 2010; Kallquist & Salzman-Erikson, 2019). While the formers can be regarded as negative repercussions of parental mental illness, the latter can be seen as a positive outcome, which I will be further discussing in a later section of this thesis.

4.2. Fear: for what could go wrong and how it can further condition my life

In addition to the guilt, fear is another commonly arouse emotion as a result of having a parent with mental health difficulties and the instability and unpredictability of the conditions these individuals have had to put up with throughout their lives. First, and quite prominent and in line with previous research is the fear of inheritance, and consequently; as many of my participants added, of becoming a burden for others, which all my participants wanted to avoid at all costs. This perhaps imply that subconsciously, even though most of them do not openly state it, their parent's illness does feel like a burden and hence their fear of following their ill parent's path and becoming a burden themselves as well. Second, most of my interviewees feared that their ill parent would get worse in the future, and subsequently, the demands place on them would increase. Therefore, some of my participants feared their parent's relapse for how this could further condition their futures. Lastly, participant did not only mention how their own subjective experience of fear shapes their circumstances, but also underlined how a generalized

societal fear towards mentally ill people often determined how much helped they could ask for and expect from outside their domestic worlds, and how supported they felt.

Overall, a large part of the fear that was discussed above seemed to stem from one common reason, which generally is the lack of education and information available to the lay people about mental health issues, their causes and how to prevent, manage and treat them. However, this lack of information was recognized by all my participants as one of the biggest handicaps to effectively tackle mental health as a society. Therefore, I will come back to this issue later in my thesis.

4.3. Independence as a double -edged sword

The one common adjective used by each of my participants to describe themselves was "independent", either because of the lack of attention received from their parents while growing up and/or their need to take over certain roles within the family that do not necessarily correspond with their age and place as a daughter. Every single one of my participants expressed a high feeling of self-sufficiency and reported maturing earlier and being more mature for their age compared to others.

In every single interview, developing independence was described as a positive outcome of parental mental illness. For example, Elena said:

"It (mum's mental illness) has made me mature earlier and to become aware of certain things that perhaps people my age are not aware of, and also to be more independent and have things clear and not fool around".

Among all my interviewees these acquired characteristics seem to be a source of pride and a key aspect of their personality and to some extent their identities, that participants seem to like this of themselves, as it often distinguishes them from others and might even make them feel special. However, as Elena continues to say, "*because in the*

31

end of the day I just got myself to rely on for any inconvenience, or anything really" (reason why she does not fool around and has things clear*)*. So, I believe that regardless of the benefits found on being independent, this has most often been forcefully developed. In other words, as Elena's quote reflects, because they had no one else to rely on for support and help, these individuals have often had no other choice but to mature earlier and developed an outstanding sense of independence in order to be able to look after themselves and in some cases, after others in their families as well. In fact, my interviewee Isabel, when asked about how she felt about how parental mental illness affects her life, she described it as it *"obliged me to mature a little bit earlier than the rest"*.

In fact, in line with previous research as well, this independence has sometimes forced individuals into taking more responsibilities on their shoulders that what they are prepared for, or from what correspond to them in the first place. In fact, we see it in the case of Ines, who in the perceived absence of her mum to provide guidance to her younger sisters, she took over the caring responsibilities and as a result, she often feels that she has too many things on her plate and sometimes struggles carrying everything forward.

Additionally, as a result of feeling very independent, my interviewees Olivia, Elena and Jimena who describe their mums as more dependent on others than they are, and used to look down on their ill mothers for it, reported sometimes experiencing as if they have exchange roles with their mothers; as they feel that they looked after their mums more than their mothers did for them and/or they have to worry more about them. Moreover, these also report a wish for their mothers to be a little bit more independent as well. Indeed, avoiding at all costs to be dependent on others like their mums is also another reactive response to parental mental illness that has also been commonly identified among my participants as a motivator to develop high levels of independence, maturity, and self-reliance.

4.4. Negotiating responsibilities and setting boundaries

If there was a word that was mentioned extensively throughout my interviews that was "responsibility". In line with the previously mentioned role-exchange perceived by some of my interviewees, often my participants reported feeling like they had the responsibility of taking care of their mentally ill parent, and for some, as for the cases of Isabel and Jimena, of their siblings as well. Interestingly enough, even though participants commonly describe the feeling of "*having the responsibility*" to take care of their mentally ill parent, as an obligation, they also reported that *"in the end of the day I know that I do not really have any sort of responsibility over her,"* said Olivia. Similarly, Ines recognizes that because she is by default a responsible person, she has been delegated many tasks within her family that do not correspond to her and that she nowadays considers that it should not be her responsibility.

Moreover, Jimena sees how other families, parents and children live their own lives and *"I should not feel like I have a responsibility towards them, neither a burden, nor feel guilty, yet sometimes I do feel it and it makes me feel bad"*. However, in the end it does seem that Jimena has mixed feelings about feeling responsible for her mum, because while on the one hand she describes feeling responsible for her mum as a setback because it does not completely allow her to live an independent life with her partner, on the other hand she feels like she ought to feel responsible for her mum and her mum's recovery, simply, because it is her mum and she wants to be alongside her in the journey. However, as she and others similarly shared, it is hard as well to draw the boundary between overprotection and normal expectations for care towards a mentally ill parent.

Ines further recognizes that it is very hard to negotiate how much weight one carries because *"in the end of the day it is your family, and you feel like you have a*

responsibility towards them". Likewise, in her quest to avoid certain behavioral patterns that she has acquired as a result of being a caretaker for her ill dad for a long time, to further condition her future, she recognize feeling responsible for what happens to her family and finds herself in a negotiation between what is normal to be expected from her by her family and what should be the state's responsibility to provide care for its citizens. She further reports how this negotiation is meant to be resolved by her own ethics and morality, which she struggles with. In addition, the struggle to draw boundaries further applies to what Maria described as the ability to distinguish between what is a direct result of their parent's illness and what stems from their base personality and/or have been developed as a result of them "getting comfortable" with being dependent on others for care.

Overall, participants seem to share a common feeling of responsibility towards their mentally ill parent. However moral values and cultural notions of family loyalties and solidarity seem to play a role in how individuals negotiate their responsibilities and set boundaries. The latter are particularly difficult to stablish as they are often fluid and mobile and go from setting boundaries with the self by for example putting self-care first, to setting boundaries with others by for instance learning how to not allow others to overstep the boundaries you have stablished for yourself, or when to be more understandable with parental mental ill versus recognizing when one is being taken advantage of.

Chapter 5: Recycling negative life experiences for positive outcomes

"If what happened to me would have never happened – which to be clear I would not like to re-live it or to ever have it had happened to me, because I am not going to romanticize it, so, I want to underline that if given the chance I would have liked to not have lived through it because it destroyed me and I have needed to reconstruct myself from it– yet, if it would not have ever happened to me I recognize that I would not be able to be or I would not be able to continue being the person I am today, that I have clear." – Amanda

In this section I want to focus on how my participants describe how despite the challenges they have faced as they learned how to live with parental mental illness, they all have managed to get something good/useful out of it. Hence, I called this recycling negative life experiences for positive outcomes.

5.1. The will to improve

Overall, there seems to be a high level of self-awareness and introspection within all my participants. As a result, all of them devoted special attention to their journeys of self-understanding and exploration, and all manifested a desire for self-improvement. Participants were able to reflect on traits and characteristics of themselves that they wished to improve on and/or to change, and all felt very motivated to become the best version of themselves. They were also aware that the journey of self-discovery is long and tedious, however, they were all ready to embark on this journey and embrace the setbacks on the way.

Sometimes, one of the main motivators to change and better themselves was to avoid becoming like their ill parent. For instance, Maria says:

"There are certain habits and traits that resemble my mum's and that I do not want to have and that I am trying to change to not be like that and to improve in certain things".

However, this is not necessarily a bad thing, as in the way that Elena puts it:

"(*having a mother with a mental illness) it gives you a model to avoid (...) so in the moment that something happens you are the first one to recognize the warning signs and are ready to avoid repeating the pattern (...) you are more ready than perhaps someone who has never lived through it and therefore is not ready to see the signs or understand what is going on within themselves, so they end up falling into a darker hole."*

Other times the desires to work on themselves arises from the desire to improve the living atmosphere at home and the relationship with their family. However, they also recognize the challenges along the way of change, especially when they feel like there is already too much on their shoulders. For example, as Ines manifests*:*

"I believe that there are still things that I need to work on, because even though I understand her mental illness and try to be patient with her and adapt to her needs, however, I sometimes feel anger because I do not see anyone else trying to understand her (Ines' mum) and trying to collaborate".

Altogether, participants frequently recognize the need as well to get to know the self in depth in order to not only avoid becoming like their mentally ill parent but also to be able to live a more fulfilling and rewarding life. In fact, most of them have reported growing into a more curious person in terms of wishing to understand their triggers and reflect on their own behaviors. Overall, all my participants recognized that being curious and learning about oneself and a readiness to work on one's flaws are essential to wellbeing and live a full life. They also recognize that with time they have become better

at recognizing areas of improvement within themselves. As a result, many of my participants reported feeling comfortable with who they are, and confident and resourceful enough to manage themselves and avoid repeating maladaptive patterns of behavior from their mentally ill parent.

5.2. Developing personality assets and defining career paths

Many of my participants also described that as a result of living next to someone struggling with mental health, they have developed certain skills and traits – besides independence, which we talked about before in a previous chapter, that they feel happy and proud of to have – and which in contrast with independence it does seem to mostly benefit them. For example, Ines, Jimena, Maria and Olivia, all mentioned their ability to empathize and to be sensitive and understanding, as key outcomes of living with parental mental illness. Additionally, they believe that these traits allow them to better connect and help others, which in fact brings them high levels of satisfaction. Moreover, developing strength is another personal asset of which many of my participants feel very proud of. Even though this resilience to endure living difficult life situations often stems from living through hardships and overcoming challenges, there seems to a general acknowledgement among my participants that "*suffering is key for change and often essential to bring the best out of people*", as Amanda put it.

In addition, developing these qualities and having gone through certain life experiences that are entailed to parental mental illness have inspired some of my participants career paths and study interests. From Amanda who later in life changed career paths to study Sociology to be able to understand herself better, to Ines who believes that it is because of her abilities to be a good listener, empathize, be sensitive towards other's suffering and her close contact with the role of psychologists from an

early age, that she decided to become a psychologist herself, and finally to Elena, who believes that her assertiveness and ability to take "big" responsibilities – developed by having to manage difficult life situations by herself form an early age, will make a good policeman.

In general, all my participants recognize the struggle of living with parental mental illness, and even though they sometimes wish for things to have been different, they seem to choose to believe that "*in the end of the day everything is an opportunity for self-growth and if you chose to do so you can always pick something positive out of a situation,"* as Ines explained. In fact, as my participant Amanda further asserts:

"There are people, who are able to make out of their suffering and pain something very positive for themselves and who can transform it into very positive outcomes at a social level for others around them."

Indeed, in my participants narratives, we see how many of my participants by developing personal assets do not only improve their own wellbeing, but also are able to help others within and outside their family circles.

Chapter 6: Spain's mental health care system under review

When asked about their experiences with the mental health care system in Spain, most of my participants had zero hesitation in describing their experiences as awful, unhelpful, and unsupportive. Even though some of my interviewees when asked to give their opinions on how the Spanish public health care system deals with mental health patients, very humbly recognized that they are not an expert on the matter so they were not very sure about what to tell me, I considered that in contrast with what they believed they were true experts in the subject, because they all have had direct contact and experience with the services. Hence, in my opinion if there was someone who was knowledgeable enough to give feedback, that was them. In fact, after reinforcing the value of their first-hand experiences as a key source of expertise, many of my participants felt more confident on giving their own opinions and to outspokenly recognize the pitfalls of the system, under their own personal experiences.

6.1. Less drugs and more psychotherapy

One of the most shared complains among all my participants was the extensive prescription of drugs favored by most psychiatrist as the preferred and sometimes unique treatment option for their mentally ill parent. For example, Ines showed frustration at how:

"*Most of these illnesses (mental health problems) are focused on medication (…) the treatment options are always revolving around lowering down or increasing up the dose of the medication – which indeed helps so that she does not have an acute crisis but then she is left feeling lethargic and apathetic, so in the end medication does not treat all the symptoms*".

Overall, this frustration towards the overly emphasis on drug treatment and how these prove to not be fully effective was particularly highlighted by all my participants. Moreover, all of them were strong advocates for the diversification of treatment options. Particularly, they favored psychological therapy. In fact, each of my participants mentioned that what their mentally ill parent really needed was a psychologist instead of more or different drugs. Even though most of them believed in the continuation of medication, there seemed to be a consensus that this alone is not effective, but rather it is crucial for it to be combined with other forms of psychological therapy. Furthermore, highlighting the importance of having more and better trained psychologists to counteract the dominant approach of medication prescription.

On the one hand, all my participants seemed to acknowledge that a lack of funding was to blame for the lack of diversity in treatment options and of available trained psychologists. Particularly, in small towns, where many of my participants came from, this seemed to be one of the most prominent problems detected. Moreover, participants also recognized that organizations targeted to help and support mentally ill patients and their relatives, as well as for raising awareness, also played an important role in easing the lives of not only patients, but also their family members. However, once again, those participants coming from smaller rural areas lamented the lack of infrastructures and resources. Hence, medication was favored as the most cost-effective form of treatment.

6. 2. Education and Stigma

On the other hand, some of my participants also blamed the lack of education as one of the reasons why sometimes the patient and their families make poor treatment decisions. For example, Jimena regrets her mum not ever receiving any sort of psychological help or treatment: *"My mum did not only have to see a psychiatrist, but she*

also needed to get therapy with a psychologist". Yet, she admits that due to her ignorance on mental health, she just trusted what she was told to do, even though now she thinks that more and better could have been done. In Jimena's words:

"Because if they (doctors) do not inform you (about all the treatment options available), you do not know what your mum supposedly really needs, so you just trust (in the health care system), no?".

In fact, I will later come back to the pressing need to invest in education and awareness in mental health, so that everyone can make better informed decisions not only in terms of treatment choice but on how to prevent and handle these problems when they arise within our own home environments.

Some of my participants further linked the problem of lack of funding to the pervasiveness of stigma around mental health. Amanda and Isabel felt that mental health is an issue that the state and the health care system wants to hide away and to pretend as if it is not there. In Amanda's words: "*what it is not seen nor named or shown, does not exist, and this is what happens here in Spain (referring to mental health problems)*." This, I find as well closely link to the lack of education at a societal level about mental health issues and which as a result do not only hinders funding but also health care workers' abilities to effectively react to scenarios related with mental health problems. For example, both Amanda and Jimena recalled receiving a very insensitive treatment by the medical professionals, because the impact on their wellbeing as a result of seeing their ill parent in such difficult state was completely disregarded, and their opinions and testimonies were totally discredited.

However, if there is not enough funding or attention being paid to the patients themselves, what can family members expect to receive? – this was some of the common

regrets expressed by my participants – who now when looking back recognize the pressing need to offer assistance to the family circle of the mentally ill patient, yet are aware of the many challenges on the way to receive the support and care they demand – such as the lack of training, intervention protocols, medical professionals and funding.

When asked about whether they would have liked to get more attention from the health-care system, all my participants undoubtedly agreed that they wished more attention would have been paid to them and how their parent's mental illness affected their homes and consequently their own wellbeing. Unfortunately, all of them regret no one worrying about them and reported feeling unseen by health care professionals. On the one hand, Jimena described as "traumatic" certain experiences in her life in which she had to closely deal with the aftermath of her mum's mental illness, and she considers that she should have been supported as well, as she was quite young and going through very traumatizing instances, that only now she is starting to understand how they might have affected all throughout her journey. On the other hand, Ines also wishes that more attention would have been given to them, as the family of the mentally ill person because perhaps she would have known better how to deal with the situation and help her mum. Additionally, Isabel believes that if family members were consulted more often about how they see the patient's recovery, these would receive more accurate diagnosis and treatments.

Chapter 7: Mental health matters – The important role of education and why we should learn about it at schools

Disinformation, ignorance, and inadequate education and information were the common denominator highlighted by all my participants for the poor management of mental health problems and their prevention in Spain. Family programs that focus on educating the relatives of the mentally ill on how to best deal with the patient, to help each other and improve communication, were often highlighted as vital by many of my participants. They often complained that due to the scarcity of services that can ease the caring function of the family for their mentally ill relative, the expectations for care mostly fall on them. In addition, a lack of training programs on how to take care of someone suffering from mental illness poses a huge challenge for the overall stability and wellbeing of the family.

Isabel highlighted that it is important to understand what the role of the family is, and if they are expected to care for their family member, they should at least be better prepared for it and of course, better supported, as well as better integrated into the patient's recovery strategy. To quote Isabel:

> *"There is no accessible information. However, when you have a "physical illness" it simply affects you, for example if you lose your mobility. Yet, when you have a mental illness, what it is really being affected is the environment, because often the individual is not even aware that they have it. Unfortunately, no one tells you anything about how to deal with it, and I think that should be the responsibility of the health-care system, to properly educate the family on what to do so that they do not waste their time trying out things that do not work or that might even worsen the situation*"

Besides the need for family education to equip families with the tools to not only care after their mentally ill family member but to look after themselves and develop resilience, my participant Jimena strongly emphasized on the need to implement mental health education at school from very early on. *"We are expected to face the difficulties of life when nobody has ever taught us how to manage our own emotions"*. We see how Jimena believes that learning about ourselves and developing emotional intelligence is key to become strong individuals and prevent possible future mental health problems. In addition, she also believes that it is the role of schools to implement this into their curriculums, as she considers it to be as important as any other already taught subject such as math and literature. Additionally, she recognizes that because of her close experience with mental health problems she has been able to become very aware of how underappreciated it is to learn how to manage our own emotions and it has opened her eyes to advocate for improving its visibility in school's curriculums.

Moreover, Elena adds on to this by proposing that individuals should be taught to recognize early signs of psychopathology and to develop effective coping mechanism to prevent them from further developing. She recognizes that because of her experience living in close proximity with someone dealing with mental health problems, she is equipped to recognize the warning signs, but perhaps others who might not have encountered it from that early or close on, might not recognize the signs on time. Therefore, it is important to talk about it at schools as well as among more informal settings such as in friend circles.

Besides, Olivia also blames the disinformation around mental health as one of the main factors why some people fail to ask for help before their problems get bigger, which results in worse outcomes for the individual sufferer and its close circle. All my participants shared the opinion that wrong beliefs around what mental health problems

are and what are not and what these entail and who they can impact, are the leading causes why so many families suffer in silence and there is not enough pressure towards the system to improve, expand and diversify their mental health care and support services. To tackle this problem, my participant Amanda suggests that there should be education programs that aimed to translate scientific evidence into simple and accessible information that can be understood by lay people. Furthermore, every town, should have some sort of organization/committee, in charge of spreading the information and raising awareness.

Chapter 8: Experts through lived experience: recommendations to others

Because it is also my aim that this thesis can help others struggling through similar situations, I asked my participants that under the light of their own experiences what they would advise others to do, so that they are better prepared to endure the challenges and grow stronger from them. Hence, below I will list the most common recommendations given by my participants. As I previously highlighted, I believe that being an expert through lived experience has an infinite value that is often disregarded, particularly by those who have been "officially" academically trained to deal with health problems. However, I am sure enough to assert, and under the light of the collected narratives of my participants and my own experience, that many of the nuances of what it really entails to live with someone with a mental health problem can only be properly felt and understood by those who have really lived through it themselves. Thus, I consider that it is them who can provide the best support and advice to others dealing with similar circumstances. We need to empower their voices and see them beyond high-risk individuals to developing psychopathology and instead, view them as invaluable resources to advocate for mental health awareness and education, a diversification on treatment, the inclusion of the domestic world in how we approach and deal with mental health issues, and the creation of institutions and policies that support beyond the suffering individual but the larger environment of those affected by mental health problems.

8.1. Asking for help

The most mentioned advice that my participants had for others was to ask for help. Particularly, psychological help. Elena explains that:

"You do not know the level of resilience that each person has and maybe someone does not feel they need to, but in the long run, parental mental illness can be difficult to deal with"

– and in base of my participants narratives and my own experience, it is always challenging and troublesome –

"so, asking for professional help to simply talk about how you feel can do wonders to prevent developing any psychopathology in the future from that."

Asking for help also entails recognizing when there is too much on your shoulders. My participant Ines, regrets not asking for help in terms of re-distributing responsibilities within her household, so in the end she felt like she was carrying all the weight in her shoulders, which let her to develop some resentment towards her family for not helping her out more. However, now she advices others to ask for help because:

"Even though it is normal to feel like it is your responsibility because it is your family, there is no point in carrying all the weight because you are just going to burnout, and you are no longer going to be healthy, which is very counterproductive."

Jimena recognized though that often one of the obstacles to ask for help and support is that sometimes we develop an armor to protect ourselves from everything that goes on around us. To quote my participant:

"You try to hide it and pretend to be strong and put out a barrier as a self-defense mechanism to cope, but in the end of the day that takes a toll on you whether you like it or not because you need to face that reality, and sometimes recognizing that you cannot deal with everything on your own is the wisest thing you can do to stay sane through it all".

Jimena further adds that one of the benefits of asking for help is that it can help you to confront the situation more effectively because you are being heard by someone.

"*Your struggles are being acknowledged and validated, so you do not feel alone, and they can also provide you with the necessary tools to be able to manage those emotions*".

Furthermore, there was an emphasis on looking for professional help, such as a trained psychologist. These were deemed to be better equipped to help you. However, most of the participants agreed that overall, what really matters is that you share your struggles with someone else, so in Jimena's words:

"You need to open up to others, even if it is just to your closest friends, but talking is necessary, because at one point or another you will need to do so."

Another identified barrier in asking for help is, once again, the pervasiveness of stigma around mental health and the abundance of misinformation. Olivia pointed out that, the belief that in order to see a psychologist one needs to be dealing with very serious mental health issues is still very present. Additionally, highlights that because sometimes people still look at those who go to the psychologists as crazy, many people who would benefit from going end up not going, in fear of being look down upon or being seen as vulnerable. In contrast, Elena pointed out that among her group of friends, many people have started to normalize going to the psychologist and have started talking about it more casually, which, she believes is a step forward. However, she also recognizes that this improvement often only happens among a specific social class, the middle-upper class; those who have money to afford going to a psychologist and who can access better education. So, she is worried though that this progress is not being followed by other social classes at the same pace. Thus, pointing out to the burning problem of inequality of access due to the lack of financial means and education.

8. 2. Sharing your battles to work on acceptance

Asking for help is also linked to the need to learn how to accept the situation, which is another common advice given by my participants. To quote Ines: "*acceptance is very important to be able to build off this*". Ines described acceptance, as the need to be okay with that certain thing will never be the same – particularly referring to her mum. Furthermore, she recognizes that even though at the beginning it can be hard to talk about it and that one might not even be aware of the pervasive ways in which parental mental illness can affect them, because this often is an overwhelming experience, it is crucial to learn how to accept it. She also points out that this process in fact might happen in the long run, but that is okay as far as one is able to accept it, so to be able to grow from it. As previously mentioned, this advice about acceptance is closely linked as well to the one about asking for help, because as many participants already emphasized, asking for help, and opening up may be the first steps towards acceptance.

Chapter 9: Discussion

If there is one thing to get clear from these conversations is that once mental illness erupts in the domestic world, all parties involved are hit by it differently. So, if we only focus on mitigating the symptoms of the diagnosed patient, there is only so little that we will be able to achieve in terms of long-term recovery, prevention, and wellbeing. Yet, I want to highlight, that despite the focus of this thesis on the domestic world, I was limited on what I could do in the domestic space due to the methods I used. Thus, I was not able to really see what happens in the domestic world, instead I only relied on the spoken accounts of the adult children of mental health patients.

While the effects that mental illnesses can have on the individual sufferer are often predictable – in terms of symptomatology, the effects that these can have on the larger surrounding environment of the patient, particularly on their household, are often less frequently understood. Especially, since each individual fulfills a distinct role within the family, the effects of second-hand experience of mental illness will certainly feel different on each of them as well. If we understand kinship as a "mutuality of being", I believe that after reading my participant's testimonies it is not hard to understand how mental illness is co-experienced by everyone within the family. Particularly, their children, who given their developmental phase, are more dependent on their parents for care and support (Murphy et al, 2010). In line with previous findings, the effect that parental mental illness has on their children often does not become apparent until later and/or it is sometimes hard to recognize (Dickens & Marsh, 1994). Yet, when asked about it, all my participants were perfectly able to identify the personal legacy that growing up with a parent with mental health illness has left on them. Furthermore, beyond mental illness, the domestic world is largely influenced by the socio-cultural and political structures in place. Thus, everyone's role within the family, expectations and responsibilities are largely shaped by

the societal context in which these domestic worlds are situated. Hence, I considered worth looking at how adult children are impacted by their parent's mental health difficulty within the specific context of Spain.

In Spain, family is at the core of one's identity and sense of belonging. As a result, a strong kinship ethic is formed within families, setting the moral expectation to provide care and a safety net. However, the country's strong emphasis on family union, support and responsibility tend to single out the positive qualities of kinship ties – such as solidarity, reciprocity and trust – while often neglecting the less pleasant aspect of kinship relation, to which Audrikopoulos and Duyvendak (2020) referred to as the dark side of kindship – such as fear, abuse, exclusion – which most commonly get revealed in the face of challenges, during moments of hardship. This is visible through my participants experiences, who demonstrate a strong kinship ethic by emphasizing on solidarity, family loyalty and responsibility for care. Yet, as a result many individuals take more responsibilities than what they are supposed to and equipped for in the first place and subsequently, it sometimes poses a mental constraint on how they think they ought to live their lives and how they feel about themselves. What is even worse is that the government tends to exploit their citizens' strong kinship ethics to their benefit, to minimize costs spend on welfare and healthcare, by moving the locus of care to the home and the family. However, without providing them with the adequate training and support, so that they cannot thrive under this challenging conditions.

It seems counterintuitive that in a country like Spain, where so much emphasis is put on caring for and being grateful for one's family, there is a lack of acknowledgment of how ongoing experiences in adulthood are shaped by one's family and early experiences. Therefore, if we want to prevent intergenerational continuity of mental illness and ensure the wellbeing of every family member, it is high time to start treating

the domestic world as a real unit, by assessing the effects of mental illness on each individual and providing particular care and attention, rather than isolating the effects of mental illness to individual patients.

9.1. Recommendations

While the personal legacy of having a parent with mental health difficulties cannot be completely erased, perhaps if these people are better informed and supported, the most negative repercussions, such as the feelings of guilt and fear that my participants mentioned, can be minimized. If the individual state of those conforming the domestic world are inseparable from the larger state of their intimate others (Gammeltof & Oosterhoff, 2018) it is reasonable that parental mental health does condition one's life and thoughts. However, with the appropriate support system in place — so, that the burden and responsibility of care does not unanimously fall on to the family, or on to particular individuals within the family –, and an efficient educational program that makes information accessible to understand how to deal with mental health problems when they erupt within the family and how to protect the self from developing them, the children of parents with mental health issues might have better chances of fostering better outcomes from their challenging experiences rather than negative ones.

So, the call for a more holistic assessment of the domestic world of the mentally ill patient is expected to first alleviate the pain and suffering of the family, by providing a broader support network, coping tools and resources, and reliving the family members from some of the associated burden of having a mentally ill family member at home. Second, it is expected to disseminate more and better information across households so to know how they can best support the mentally ill patient as well as each other and third, it is also expected that by including as many parties as possible into the conversation,

medical professionals will provide more accurate diagnosis and treatments that will accelerate the prospects of recovery.

Additionally, including male participants and interviewing older adults who might already have their own families and are now parents themselves might also be interesting to include for further investigations on the adult legacy of having a parent with mental health difficulties, since age and gender might play a role in the way in which individuals process their life- circumstances and how they accept their situation (Dickens & Marsh, 1994). However, this was beyond the scope of this thesis.

Conclusion

With increased awareness on mental health problems and their rising number within our society (The European Mental Health Action Plan 2013–2020), I believe that it is crucial that we look beyond the impact that these can have on the individual patient itself, and also focus on the broader impact on the patient's environment, particularly on the domestic world. By asking the question: *What is the legacy for adulthood of having a parent with mental health difficulties in Spain?* This thesis have highlight that indeed having a parent with mental health difficulties poses difficult challenges to the development and wellbeing of their children. Throughtout this thesis I have shown that repercussions can often be placed on a spectrum rather than in a binary. However, I` have also shown that there are certain emotions such as fear and guilt that can be located towards the more negative side of the spectrum. Additionally, while the feelings of increase independence and maturity are generally understood by all my participants as positive outcomes, they are also signs to be wary of, as often these traits tend to also manifest as taking responsibilities to the point that they overwhelm them. Also, role-exchange between parent and offspring creates difficulties in drawing boundaries and prioritize self-care. Yet, there is as well some sort of hope and appreciation towards the hardships experienced by all my interviewees, which does not aim to romanticize their experience, but rather to acknowledge that one is always on a learning journey and that suffering often provide us with a cue to grow and sometimes even to create something good out of it.

In addition, I aimed to enrich the research on the children of parents with mental health difficulties by situating this experience into the socio-cultural context of Spain, to illustrate how individual experiences are deeply tight to the larger society – to its

dominant values, traditions and expectations. I hope that through the understanding of Spain, as a country with strong family loyalties that have sustained inter-generational micro-solidarities (Moreno & Marí-Klose, 2013), I have been able to bring an additional lens to understand how subjective individual experiences with parental mental health difficulties are deeply tight to and shaped by the socio-cultural and political context. Indeed, my research shows how the pervasiveness of familistic values adds pressure on to my participants' feelings of duty towards their mentally ill parent and permanent need of doing more and better. Moreover, these values permeate the welfare and health-care systems and so, the lack of resources, and support in place to this families, increase the feeling of burden, the responsibility for care and the subsequent negative impact of mental health in the domestic world for the overall wellbeing of households.

As I have mentioned numerous times throughout my thesis, it is my own personal experience with parental mental illness what propelled this research. I deeply resonate with the words of my participant Jimena*:*

"If I could choose, I would not ask for this to happen to me again, but I recognize that if it was not for it, I would not be the person I am today."

Because indeed, I would not choose this again upon myself either. However, given that I cannot change the circumstances, the only option left is to embrace the reality and at least make something useful out of it, something helpful, something that I myself would have wished to have—the opportunity to openly acknowledge and raise awareness of how difficult and tumultuous having a parent with mental health illness can be for your family and the impact it can have on your personal wellbeing and life satisfaction. Moreover, the chance to not feel like the only one going through something like this, and to have our voice heard in terms of what we think should be improved to provide adequate support for us. Therefore, this project is to me my way of recycling negative life

experiences into positive outcomes. I hope that this is already a steppingstone to increase the visibility of this collective, so that our voices can be empowered, respected, and that we can finally receive the support and acknowledgement we deserve.

Bibliography

Aiken, L., et al. (2012). "Patient safety, satisfaction, and quality of hospital care: Cross sectional surveys of nurses and patients in 12 countries in Europe and the United States." *The BMJ*, *344*, e1717. doi:10.1136/bmj.e1717

Andrikopoulos, A., & Duyvendak, J. W. (2020). "Migration, mobility and the dynamics of kinship: New barriers, new assemblages." *Ethnography*, *21*(3), 299–318. https://doi.org/10.1177/1466138120939584

Carbonell Marqués, A., & Navarro-Pérez, J. (2019). "The care crisis in Spain: an analysis of the family care situation in mental health from a professional psychosocial perspective." *Social Work in Mental Health*, *17*(6), 743-760, DOI: 10.1080/15332985.2019.1668904

Boeije, H. (2010). *Analysis in Qualitative Research*. Sage Publications, Inc

Brown, J. (2001). "Conscious, deliberate, and purposeful living: Lessons from the adult daughters of psychiatrized women." *Theses and Dissertations (Comprehensive).* 712. https://scholars.wlu.ca/etd/712

Charmaz, K. (2014). *Constructing Grounded Theory* (2nd ed.). Sage Publications, Inc.

Comas – D'argemir, D., Marre, D. & San Román, B. (2016). "La regulación política de la familia. Ideología, desigualdad y género en el Plan Integral de Apoyo a la Familia". *Política y Sociedad, 53* (3), 853-877

Confederación Salud mental España. Confederación Salud Mental España. (2022, January 13). Retrieved January 26, 2022, from https://consaludmental.org/

Dickens, M., & Marsh, T. (1994). *Anguished voices: Siblings and adult children of persons with psychiatric disabilities.* Boston, MA: Boston University, Center for Psychiatric Rehabilitation.

Davis, E. (2018). "Global Side Effects: Counter-Clinics in Mental Health Care." *Medical Anthropology, 37*(1), 1-16, DOI: 10.1080/01459740.2017.1367777

Gammeltoft,T., & Oosterhoff, P. (2018). "Mental Health in Domestic Worlds". *Medical Anthropology, 37*(7), 533-537, DOI: 10.1080/01459740.2018.1504216

Gladstone, B., Boydell, K., Seeman, M., & McKeever, P. (2011). "Children's experiences of parental mental illness: a literature review". *Early Intervention in Psychiatry, 5*, 271–289 doi:10.1111/j.1751-7893.2011.00287.x

Harding, S. (1991). *Whose Science? Whose Knowledge*? Ithaca, NY: Cornell University Press.

Hesse-Biber, S., & Piatelli, D. (2007). "Holistic Reflexivity: The Feminist Practice of Reflexivity." In S. N. Hesse-Biber (Ed.), *Handbook of Feminist Research: Theory and Praxis*, 493-514. Sage Publications, Inc

Hooks, B. (1994) *Teaching to transgress: Education as the practice of freedom*. New York: Routledge

Kallquist, A., Salzman-Erikson, M., (2019). "Experiences of Having a Parent with Serious Mental Illness: An Interpretive Meta-Synthesis of Qualitative Literature". *Journal of Child and Family Studies 28*:2056–2068 https://doi.org/10.1007/s10826-019-01438-0

Kezar, A., & Lester, J. (2010). "Breaking the Barriers of Essentialism in Leadership Research: Positionality as a Promising Approach". *Feminist Formations, 22*(1), 163-185, https://doi.org/10.1353/nwsa.0.0121

Leijdesdorff, S., van Doesum, K., Popma, A., Klaassen, R., & van Amelsvoort, T. (2017). "Prevalence of psychopathology in children of parents with mental illness and/or addiction". *Current Opinion in Psychiatry, 30*(4), 312-317 doi: 10.1097/YCO.0000000000000341

Leitner, S. (2003). "Varieties of familialism: The caring function of the family in comparative perspective." *European Societies, 5*(4), 353-375, DOI: 10.1080/1461669032000127642

Maybery D., Reupert, E., Patrick, K., et al. (2009). "Prevalence of parental mental illness in Australian families." *The Psychiatrist, 33*, 22-26. doi: 10.1192/pb.bp.107.018861

Moreno, L., & Marí-Klose, P. (2013). "Youth, family change and welfare arrangements." *European Societies, 15*:4, 493-513, DOI: 10.1080/14616696.2013.836400

Murphy, G., Peters, K., Jackson, D., & Wilkes, L. (2010). "A qualitative meta-synthesis of adult children of parents with a mental illness". *Journal of Clinical Nursing, 20*, 3430–3442 doi: 10.1111/j.1365-2702.2010.03651.x

Nicholson, J., Biebel, K., Hinden, B., Henry, A., & Stier, L. (2001). "Critical issues for parents with mental illness and their families". *Center for Mental Health Services Research*

Novella, E. (2008). "Theoretical accounts on deinstitutionalization and the reform of mental health services: a critical review." *Med Health Care Philos 11*(3):303.

Sahlins, M. (2011). "What kinship is (part one)." *Journal of the Royal Anthropological Institute 17*(1):2–19. doi:10.1111/ jrai.2011.17.issue-1.

Salvador – Carulla, L., Costa-Font, J., Cabases, J, McDaid, D.,& Alonso, J. (2010). "Evaluating Mental Health Care and Policy in Spain." *The Journal of Mental Health Policy and Economics 13*, 73-86

Sanjari, M., Bahramneshad, F., Fomani, F., Shoghi, M., & Cheraghi, M. (2014). "Ethical challenges of researchers in qualitative studies: the necessity to develop a specific guideline." *Journal of medical ethics and history of medicine, 7*(14). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4263394/

Simpson-Adkins, G., & Daiches, A., (2018). "How Do Children Make Sense of their Parent's Mental Health Difficulties: A Meta-Synthesis". *Journal of Child and Family Studies, 27*:2705–2716 https://doi.org/10.1007/s10826-018-1112-6

Snell-Rood, C., Richard, M., & Schoenberg, N., (2018). "Negotiating the interpretation of depression shared among the kin". *Medical Anthropology, 37* (7): 538-552

The European Mental Health Action Plan 2013–2020. Retrieved April 3, 2022, from https://www.euro.who.int/__data/assets/pdf_file/0020/280604/WHO-Europe-Mental-Health-Acion-Plan-2013-2020.pdf

The global survey of Family Caregivers (C4C). Caring for Carers (C4C) survey. Retrieved January 27, 2022, from http://www.eufami.org/c4c/region/spain.html

Vázquez-Barquero, J., & García, J. (1999). "Deinstitutionalization and psychiatric reform in Spain". *European archives of psychiatry and clinical neuroscience*, *249*(3), 128–135. https://doi.org/10.1007/s004060050077

Weiss, H. (2022). "A family matter: Responsibility and selfishness in Spanish Households". *Feminist Anthropology*, DOI: 10.1002/fea2.12078

Wepf, H., Joseph, S., & Leu, A. (2021). "Pathways to Mental Well-Being in Young Carers: The Role of Benefit Finding, Coping, Helplessness, and Caring Tasks". *Journal of Youth and Adolescence, 50*:1911–1924

Consent for Participation in Interview

I volunteer to participate in the research project conducted by Gema Benavides Jimenez, from University College Utrecht and for the purpose of her bachelor thesis. I understand that the project is designed to gather information about the experiences of adult children of parents with mental health difficulties.

1. My participation in this project is voluntary. I understand that I will not be paid for my participation. I may withdraw and discontinue participation at any time without penalty. If I decline to participate or withdraw from the study, no one will be told.

2. I understand that if I feel uncomfortable in any way during the interview session, I have the right to decline to answer any question or to end the interview.

3. Participation involves being interviewed by a student from University College Utrecht. Notes will be written during the interview and the interview itself will be recorded.

4. I understand that the researcher will not identify me by name in any reports using information obtained from this interview, and that my confidentiality as a participant in this study will remain secure. Subsequent uses of records and data will be subject to standard data use policies which protect the anonymity of individuals and institutions.

5. I understand that the student's supervisor may have access to raw notes or transcripts for the sake of assisting the student in data-analysis. Beyond this, no other person will have access to the interview transcript.

6. I have read and understand the explanation provided to me. I have had all my questions answered to my satisfaction, and I voluntarily agree to participate in this study.

7. I have been given a copy of this consent form.

_____ _____

My Signature   Date

_____

My Printed Name

For further information, please contact:

g.benavidesjimenez@students.uu.nl

Self- introduction

- Childhood memories

Relationship with family members

- Relationship with ill parent

  - How did you find about the illness?

  - How would you describe the illness?

  - How did that make you feel? How did you react?

How did this impact you at that moment?

  - your relationships?

  - Your own mental health

  - Your own understanding of mental health now?

What do you feel that have been the most prominent consequences in your life from

these circumstances?

  - How has this affected your development

  - Your view of the world

  - Emotional state

- How has this experience marked you?

- Coping mechanisms?

Support

  - From family, Friends

- Sharing situation with others

  - Taboo? Secrecy?

  - How did it make you feel?

Opinions of mental health care system

- Treatement

- Support received

- How has the treatment/ labels used over your mum have shaped how you view her and you relate with her?

Attitudes from the larger Spanish society

- How is mental health tackled?

- How is mental health talked about?

- What is to improve?

Tips for people under similar circumstances

- Things you would like to work on/ improve

- How would you have felt better guided?

Closing questions

- How did this interview make you feel?

- Would you have liked to be asked anything else?