

When someone you love has bipolar disorder: Experiences of family members

by

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## ABSTRACT

This manuscript thesis is written in an attempt to provide a glimpse of the experience of family members caring for a loved one with bipolar disorder. Positive and negative aspects that caregivers to loved ones with bipolar disorder experience are discussed. The potential medical implications from a genetic standpoint of children of individuals with bipolar disorder and firsthand accounts of how children experience having a parent with bipolar disorder are discussed. The experiences that caretakers have when interacting with medical professionals and recommendations as to how to improve these interactions are also explored. Findings are summarized in the final chapter, a discussion of the limitations of the work is offered, and concluding remarks are made.

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## TABLE OF CONTENTS

ABSTRACT .....	ii
ACKNOWLEDGEMENTS .....	iii
DEDICATION .....	iv
TABLE OF CONTENTS .....	v
CHAPTER 1: INTRODUCTION .....	1
Purpose of the Study .....	2
Scholarly Context.....	3
Definition of Terms.....	3
Situating the Author .....	4
Thesis Overview .....	5
ESSAY 1: FAMIY MEMBERS CARING FOR LOVED ONES WITH BI-POLAR .....	6
Bipolar Disorder in the DSM-V.....	6
Living at and Impact on Home .....	7
Positive Aspects .....	8
Infringement of Lifestyle of the Caretaker .....	9
Stress .....	12
Stigma .....	19
Conclusion .....	20
ESSAY 2: CHILDREN OF PARENTS WITH BI-POLAR DISORDER.....	21

Children of Parents With Bipolar Disorder: Risk Factors .....	21
Mood Disorders .....	22
Thought Problems.....	23
Disturbance/Poor Interpersonal Functioning .....	24
Disinhibition .....	25
Sensitivity to Stress.....	25
Negative Family Milieu .....	26
Children’s Experience of Growing up with a Parent with Bipolar Disorder .....	27
Positive Experiences Resulting from Having a Parent with Bipolar Disorder .....	28
Taking on More Responsibility .....	29
Fear of Developing Bipolar Disorder .....	31
Inconsistent Parenting.....	31
Isolating Themselves Because of Parents Bipolar Disorder .....	33
Effects Felt by Children as a Result of Having a Parent with Bipolar Disorder .....	33
Ways Children Coped with their Parents Bipolar Disorder .....	34
Conclusion .....	36
<b>ESSAY 3: HOW TO PROVIDE BETTER SUPPORT FOR FAMILY MEMBERS CARING FOR LOVED ONES WITH BI-POLAR DISORDER.....</b>	<b>37</b>
Implications of Not Having Enough Support for Caregivers .....	37
Over Involvement of Caregivers: A Move Away from Institutions to Home Care.....	38

Problems with the Current Methods of Treating Bipolar Disorder .....	39
Misdiagnosing Bipolar Disorder.....	39
Early Release from Hospitals.....	40
Not Treating the Whole Person.....	41
Recommendations to Improve Relationships Between Caregivers and Health	
Professionals/Counsellors .....	42
Recommendations for Caregivers.....	44
Conclusion .....	46
Chapter 5: CONCLUSION .....	47
Family Members Caring for Loved Ones with Bipolar Disorder .....	47
How to Provide Better Support for Family Members Caring for Loves Ones with Bipolar	
Disorder.....	48
Children of Parents with Bipolar Disorder .....	48
Implications for Counsellors.....	49
Limitations and Future Research Opportunities .....	49
Conclusion .....	50
REFERENCES .....	51

## CHAPTER 1: INTRODUCTION

Bipolar disorder may be experienced in a variety of ways. It is possible to have a diagnosis of bipolar disorder but live a relatively symptom free and carefree life. For those who are more seriously affected by bipolar disorder, it may be a very difficult experience for the individual and their families. As a result of the medical model moving away from institutions as a way of treating mental health issues over the last 20-30 years, many family members have had to step in and take care of their loved ones with bipolar disorder, most often without any training or information as to how to do so (Cuijpers & Stam, 2000; van der Voort, Goossens & van der Bijl, 2009). This may lead to the caregiver/family member(s) feeling many burdens (Maskill, Crowe, Luty, & Joyce, 2010). Burdens felt by caregivers may include increased financial burdens (for private hospitals and supplementing lost wages if their family member with bipolar disorder stops/reduces her or his work or spending sprees that may happen as a result of a manic episode) and worrying about when the next manic or depressive episode may occur and what impact this may have on the loved one and the family (Dore & Romans, 2001; van der Voort et al., 2009). Caregivers may also have negative interactions with medical professionals who are treating the individual with bipolar disorder but failing to offer support and information for the families of these individuals (Elgie & MorrSELLI, 2007; Hillegers, Reichart, Wals, Verhulst, Ormel & Nolen, 2005). Children of parents with bipolar disorder have increased probability of developing mood disorders and may suffer in the realm of social interactions. Early interventions and support for children with parents who have bipolar disorder may lead to improved outcomes (Birmaher, Axelson, Monk, Kalas, Goldstein, Hickey, Obreja, Ehmann, Iyengar, Shamseddeen, Kupfer & Brent, 2009; Ostiguy, Ellenbogen & Hodgins, 2012; Bauer,

Spiessl & Helmbrecht, 2015). For the reasons above, it is important to support families that are impacted by bipolar disorder in order to reduce their potential suffering.

### **Purpose of the Study**

With this study I aim to give a voice to the experiences of informal caregivers/family members of a family member with bipolar disorder in order to understand how we can better support these families. I will provide the reader with suggestions as to how counsellors/health-care workers can work with these families by offering empathy and meaningful information in hopes of reducing the sense of powerlessness they may feel (Travag & Kristoffersen, 2008). The aim is to provide the reader with a broader understanding of how bipolar disorder may affect families and ways in which we as counsellors/health-care workers can help to heal some of the stigma, stress, and burdens these families may feel (Jonsson, Skarsater, Wijk, & Danielson, 2011).

Bipolar disorder is the sixth leading cause of disability worldwide (WHO, 2001), and as many as 50% of people with bipolar disorder attempt suicide at least once in their lifetime (Miklowtiz & Johnson, 2006). It may account “for one quarter of all suicides” (American Psychiatric Association, 2013, p. 131). It is crucial that informal caretakers/loved ones of individuals with bipolar disorder understand this mental health issue and how to best help their loved ones while also taking care of themselves (Travag & Kristoffersen, 2008). Of offspring of parents with bipolar disorder, 52% may develop a mental health disorder compared to 29% of offspring from parents without bipolar disorder. Offspring of parents with bipolar disorder are 2.7 times more likely to develop a mental disorder than offspring of parents without bipolar disorder (DelBello & Geller, 2001). Early intervention and support of children of parents with bipolar disorder by counsellors/health care professionals may improve their overall functioning

and lessen the chances of developing mental health related issues themselves (Bauer et al., 2015).

### **Scholarly Context**

While there is much research on caregiving a person with mental illness, there is less research that specifically discusses the caregiving experience with bipolar disorder (Travag & Kristoffersen, 2008; Dore & Romans, 2001). And although there are some similarities between caregivers supporting those with other mental health issues such as schizophrenia and depression, caring for an individual with bipolar disorder may come with unique challenges.

Research on the increased risk for psychopathology/potential issues with social functioning later in life of children with parents with bipolar disorder is abundant (Bauer et al., 2015; Birmaher, Axelson, Monk, Kalas, Goldstein, Hickey, Obreja, Ehmann, Iyengar, Shamseddeen, Kupfer & Brent, 2009), however, firsthand accounts of children's experience growing up with a parent with bipolar disorder seemed far less available in research studies/journals. It would be helpful to have more firsthand accounts in order to understand what they are going through and to attempt to support these children while they are in distress instead addressing harm after the fact.

It was estimated that the direct/indirect costs of bipolar disorder on American society was \$45 billion in 2001 therefore the economic impact is also profound. Given the risks to individuals with bipolar disorder with regards to suicide and the enormous direct and indirect costs of bipolar disorder to society, more research as to how to help families coping with bipolar disorder is needed and implementation strategies in health-care systems is essential (Wyatt & Henter, as cited in Ogilvie, Morant & Goodwin, 2006).

### **Definition of Terms**

In much of the research discussed below, the word caregiver is used to describe family members (mostly married or non-married couples or sometimes parents) who have a family member that has bipolar disorder. The word caregiver is limiting in a number of ways. Firstly, it doesn't adequately describe the nature or depth of the relationship the caregiver is in. To replace the word husband/wife/partner with the word caretaker immediately diminishes the experiences the couple have outside of bipolar disorder—which could be argued to be, in many instances, the most substantial and significant part of the relationship. Secondly, the word caregiver implies that the husband/wife/partner needs to take care of her or his loved one with bipolar disorder. This is simply not the case as individuals with bipolar disorder can go years and sometimes decades without having manic/depressive episodes. Thirdly, it implies that all individuals with bipolar disorder need a caregiver, which is not the case. However, the word caretaker is the most widely used term in the research discussed below so in order to be consistent it will be used to describe individuals who have a family member (mostly husbands/wives and sometimes parents) with bipolar disorder. It should be noted that most of the research below is focused on caretakers living through the crises of bipolar disorder such as depressive and manic episodes and does not focus on the stable and healthy days in between.

### **Situating the Author**

This thesis is written from a sociological framework to better understand the experience of family members of individuals with bipolar disorder. Applying this framework allows me to unpack the experiences of caring for/being a child of a loved one with bipolar disorder in hopes that these experiences could be supported and better understood by health-care professionals/counsellors in the future. Instead of discussing bipolar disorder from a medical model point of view where diagnosis, medication, and symptom reduction are focal points, I

wanted to focus on family experiences to better understand their struggles, which I hope will help me in my future practice as a counsellor.

I am interested in this topic for two reasons. Firstly, I want to be able to offer the best support possible as a counsellor working with family members affected by bipolar disorder. I wanted to understand some common experiences that families of individuals with bipolar disorder may encounter on their journey in hopes I can offer these families compassionate support that they may not receive when encountering medical professionals. Secondly, having grown up with a family member with bipolar disorder, I wanted to more fully understand the experiences that other families had with regards to bipolar disorder. It has turned out to be a very healing experience knowing there are so many families like mine.

### **Thesis Overview**

This manuscript thesis is an attempt to provide a glimpse of the experience of family members caring for a loved one with bipolar disorder. Chapter 2 is an exploration into the positive and negative aspects that caregivers to loved ones with bipolar disorder experience. Chapter 3 discusses the potential medical implications from a genetic standpoint of children of individuals with bipolar disorder and also provides firsthand accounts of how children experience having a parent with bipolar disorder. Chapter 4 discusses the experiences that caretakers have had when interacting with medical professionals and suggests some recommendations as to how to improve these interactions. I will conclude with a summary of the findings, discussion of the limitations of the work, and concluding remarks.

## ESSAY 1: FAMILY MEMBERS CARING FOR LOVED ONES WITH BI-POLAR

In this chapter, a review of the literature of the experiences of caretakers for individuals with bipolar disorder will be discussed. Multiple studies have discussed positive aspects of being a caretaker of a family member with bipolar disorder such as increased compassion and tolerance (Baronet, 2003; Maskill, Crowe, Luty, & Joyce, 2010) while others have discussed the negative aspects of being a caregiver such as infringing on the caregivers' lifestyle and causing stress and the feeling of being stigmatized (Chang & Horrocks, 2006; Dore & Romans, 2001). In the following chapter these positive and negative aspects of caregiving will be discussed following a definition of bipolar disorder. It should be noted that bipolar disorder should be seen as located on a spectrum and not every person who is diagnosed will experience symptoms or display the behaviours discussed in this literature review (Cassano, Rucci, Frank, Fagioloni, Dell'Osso, Shear & Kupfer, 2004). While certain symptoms are necessary in order to receive a diagnosis of bipolar disorder (discussed below) many individuals go on to lead healthy lives without further episodes of depression or mania through using medication, psychotherapy, and psychoeducation to help manage their symptoms (Rogeer, ten Have, Rosso, Vollebergh, & Nolen, 2004).

### **Bipolar Disorder in the DSM-V**

Despite the potentially pathologizing affect the American Psychiatric Associations' Diagnostic and Statistical Manual of Mental Disorders (DSM) may have on individuals with so called mental disorders (a discussion of which is beyond the scope of this thesis), a definition of bipolar disorder from this manual will be given in order to provide the reader with an understanding of how bipolar disorder may present/be diagnosed in individuals. Bipolar disorder is a mental illness in which the individual experiences both episodes of major depression and

manic or hypomanic episodes. By DSM-V standards, a major depressive episode must meet five or more criteria and last two weeks or longer. In addition, one of the criteria must be either having a “depressed mood” or a “loss of interest or pleasure” (American Psychiatric Association, 2013, p. 125). A manic episode is a period of “abnormally elevated, expansive, or irritable mood and abnormally and persistently increased goal-directed behaviour, lasting at least one week and present most of the day, nearly every day or any duration if hospitalization is necessary” (American Psychiatric Association, 2013, p. 124). A hypomanic episode is similar to a manic episode but instead lasts for only four consecutive days. The DSM also states that “bipolar disorder may account for one-quarter of all completed suicides” (American Psychiatric Association, 2013, p. 131). The illness may result in the individual experiencing frequent reoccurrences of symptoms (Lam, Donaldson, Yael, & Malliaris, 2005). It is estimated that up to 15% of people with bipolar disorder die from suicide and as many as 50% attempt suicide at least once in their lifetime (Miklowitz & Johnson, 2006). Worldwide, bipolar disorder is the sixth leading cause of disability (WHO, 2001).

### **Living at and Impact on Home**

Over the last 20-30 years, health-care systems have moved away from psychiatric institutions as a way for treating mental health issues such as bipolar disorder. This has led to a significant increase in individuals with mental health issues living at home with their relatives and being cared for informally by non-professional caregivers (Cuijpers & Stam, 2000). This shift from institutionalized care to family based care has increased the responsibilities of families/spouses/children to care for their loved ones with mental health issues such as bipolar disorder (van der Voort, Goossens & van der Bijl, 2009). Further discussion of children with a parent with bipolar disorder and the implications of this will follow in the next chapter.

In the literature discussing the impact of having a family member with bipolar disorder, some caregivers' site positive aspects of being informal caregivers (Maskill et al., 2010; Baronet, 2003), while others site burdens associated with this role such as the change to their lifestyle, stress, and stigma caused by the behaviour of their family member with bipolar disorder (Lam et al., 2005; Maskill et al., 2010; Elgie & Morselli, 2007). In order to develop pragmatic, helpful, and appropriate solutions for families struggling with bipolar disorder, it is first important to identify and understand the struggles they are going through (Renaires, Vieta, Colom, Martinez-Aran, Torrent, Comes, Goikolea, Benabarre, Daban & Sanchez-Moreno, 2006). It should be noted that not all of the research discussed in this chapter will be transferable as in some cases, such as in Maskill et al., 2010, the participants of the study appeared to be homogenous in that all participants had to speak English, be supporting someone aged 15-35, with other optional criteria such as having to be financially supporting their spouse/spouse equivalent with bipolar disorder. These specifications leave out many individuals who may have had different experiences as caregivers (because they may be older than 35 for example) but couldn't be included because they did not meet the above criteria. These limitations are important to mention but it is beyond the scope of this thesis to critique every article used. In the following section, positive and negative aspects associated with being an informal caregiver to a person with bipolar disorder will be discussed.

### **Positive Aspects**

Being a caretaker to a family member with bipolar disorder can have positive effects on the caretaker such as feelings of fulfillment (Baronet, 2003) and increased compassion for a loved one and others affected by mental health issues (Maskill et al., 2010). In Maskill et al., (2010) study of 12 participants who identified as being the primary caregiver and spouse to

someone diagnosed with bipolar disorder, positive aspects of the caregiving role came to light. One participant in the above study said: “It has had positive spin offs. I think I am a much more compassionate person. I hear the news and I don’t immediately jump to the conclusion that it’s a bad person” (Maskill et al., 2010, p. 538). Another spouse felt pride and love for the individual for whom they were their primary caregiver to, “It has given me immense love and pride in her, in supporting her actually. I think she’s done incredibly well” (Maskill et al., 2010, p. 538). Another participant discussed becoming closer with their spouse “I think the trust between us is even stronger, the love even deeper, the admiration even more” (Maskill et al., 2010). In their study of caregivers (of which 61% were female, over a quarter of whom were over 60 and a parent of the individual with bipolar disorder), Dore and Romans (2001) found similar results with one participant stating “Our relationship is stronger now because of the illness” (Dore & Romans, 2001, p. 151). Again this study may not be transferable as the population was not inclusive of a variety of age groups, cultures, etc.

In addition to the positive aspects of caretaking for an individual with bipolar disorder, negative burdens have also been reported. These burdens broadly speaking fall into three categories, infringement on lifestyle, stress, and perceived stigma of caretaking for an individual who has bipolar disorder (Maskill et al., 2010; Reinares et al., 2006; Lam et al., 2005; Baronet, 2003 & Trijntje et al., 2009) .

### **Infringement of Lifestyle of the Caretaker**

Bipolar disorder has serious implications for those living with it and on those who are supporting the person with bipolar disorder (Maskill et al., 2010). Studies have shown that episodes of bipolar disorder can increase as a result of discord between caretakers and people with bipolar disorder so it is important that stressors be understood in order to protect the health

of the individual with bipolar disorder and her or his caretakers (Miklowitz, 2007). After the initial diagnosis, caretakers may feel unprepared and ill-equipped to deal with their loved one with bipolar disorder—they may have expected help from health-care professionals, but not received any (Tranvag & Kristoffersen, 2008). This will be discussed further in Chapter 4.

When persons with bipolar disorder are going through a manic or a depressive episode, caretakers' lifestyles can become greatly infringed upon by the numerous responsibilities involved in supporting an individual with bipolar disorder. Many sacrifices on the caretakers' hobbies, socializing, and personal freedom result from responsibilities taking up the time they used to spend on other activities (Chadda, Singh, & Ganguly, 2007). Managing day to day care such as helping the individual with taking medication, eating, bathing, cleaning up, and regular daily life—depending on the severity of the disorder—can be exhausting (Chang & Horrocks, 2006). Many caregivers feel isolated and alone in their caretaking activities and struggle to maintain normality in their daily lives (Jonsson, Skarsuter, Wijk, & Danielson, 2011). Many caregivers have to take time off work in order to dedicate themselves to their family member with bipolar disorder, which results in financial pressures (Lam et al., 2009). Additionally, the person with bipolar disorder may also have to take time off work, so the financial strain can be doubled (Dore & Romans, 2001).

Much of the research regarding caretakers focussed on the enormous amount of time worrying about their family member with bipolar disorder (Lam et al., 2009; Jonsson et al., 2011; Ogilvie et al., 2005). These worries include worrying about inconsistent parenting as a result of caretaking duties taking up too much time or simply because the parent with bipolar disorder cannot offer as much parenting support as they would like because of a depressive or manic episode (Aiken, 2011). Caregivers and individuals with bipolar disorder also worry about

whether or not this disorder will be passed on to their children (Aiken, 2011) (this will be further discussed in the next chapter). Caregivers worry they may be contributing to the illness and potentially making things worse (Dore & Romans, 2001) as a participant in the following study discusses,

I have turned myself inside out. Did I do something that caused this? But for the life of me, I can't think of anything that's happened or that I've done. There was one thing, and that was when we moved from the house where we lived to one of those apartments, you know the kind that are joined together, the houses. We wanted to try and see what it was like living like that. She was really happy at the old place where we lived...I've thought an awful lot about whether that was something but I can't think of anything. It just ended up this way. (Jonsson et al., 2011, p. 32)

They also tend to worry about not doing enough, which can make them feel sad but also exhausted (Tranvag & Kristoffersen, 2008). They worry about the lost potential of their loved one and wonder what will become of her or him in the future. In addition, they worry because they feel psychiatric hospitals can release their loved ones even though they are not better, which leads to more worry and feeling overwhelmed (Maskill et al., 2010).

Caretakers married/in partnership to an individual with bipolar disorder may worry about their family member becoming withdrawn (during depressive episodes) or over sexual (during manic episodes) and this greatly impacts the sexual relationship as well as the overall relationship between the couple as the caregiver does not know what to expect (Lam et al., 2005). In their study Lam et al. (2005) discussed that male and female caretakers reported a lower level of sexual satisfaction when their partner with bipolar disorder was depressed or manic. Male partners were more likely to report they avoided sexual contact and had trouble

discussing their sexual needs with their partner, while their female partners with bipolar disorder experienced problems with vaginismus (painful, spasmodic vaginal contractions of the vagina) during manic and depressed episodes (Lam et al., 2005). Men who have bipolar disorder discussed having problems with impotence and premature ejaculation during their depressive episodes and sexual intimacy may be infrequent (Lam et al., 2005). Inanli, Ibrahim, Tahsin, Mehmet, Mehmet, Caliskan, and Yilmaz (2015) found that 75% of the female participants felt that their partner divorced them because of their disorder/medication use and many of the participants with bipolar disorder (both male and female) made the decision to marry their partner during an active episode of either mania or depression. The impact of taking pharmacological drugs (for either partner) may further negatively impact the sex life between couples but a discussion about this topic is beyond the scope of this chapter.

In their study Lam et al. (2005) interviewed 37 partners of individuals with bipolar disorder in order to best understand their experience. The participants had to be either married or living with their partner with bipolar disorder for at least three years. It should be noted that participants were only recruited from two outpatient psychiatric facilities for persons with bipolar disorder in South London and Maudsley Trust and only heterosexual couples participated, which again limits the ability of this study to be transferable to the general population. The study showed that caretakers had trouble balancing the needs of their loved one with bipolar disorder with their own needs (Lam et al., 2005). Caretakers also frequently experienced stress as a result of having a bipolar family member, which will be discussed in the next section.

## **Stress**

Family members/loved ones of those with bipolar disorder may experience many forms of stress such as managing day to day life for their family, taking care of their loved one (encouraging them to shower and take their medication), and taking abuse mentally and sometimes physically from their loved one especially during manic episodes (Chang & Horrocks, 2006). Caregivers stress is heightened during hospitalization and while more severe symptoms are present (Goossens, van Wijngaarden, Knoppert-Van Der Klein, & Van Achterberg, 2008).

These stresses have been described as continuous and not just in phases of mania and depression:

When you've lived with it year in year out and you've had a lot of disappointments and you've seen a lot of set backs then you just, you get a bit sort of, well weary. A bit hopeless about it perhaps. So what we're talking about is the duration. It's like anybody with any sort of trial or difficulty. That you know, most people cope with things, like say a manic spell or whatever, there's a crisis here and oh my gosh it's terrible. You go through it all, you get over it and that's that, but when it comes back and it's again, and it's again and so on, it just gets pretty oppressive. This is not year one, this is year twenty one and I am exhausted with it mentally and physically and I have to, I can't deny it, it's there but I just have a much more sort of jaded weary response to it (a long term spouse).  
(as cited in Maskill et al., 2010, p. 539)

In Reinares et al.'s study (2010) of caregivers' burden of which individuals whom had lived with a partner who had bipolar disorder for over one year and was considered to be a significant and influential person in the family member with bipolar disorders life, various forms of caregiving stress were discussed (Reinares et al., 2006). They interviewed 43 partners of individuals with

bipolar disorder and excluded partners of individuals who had comorbid disorders, mental retardation, non-stabilized non-psychiatric illness or lived alone. As a result of these exclusions, these findings will not be transferable to the general population. One of the biggest forms of stress comes from the individual with bipolar disorders' behaviour, such as hyperactivity, irritability, sadness, withdrawal, violence, impulsive spending, depressive mood, suicidal ideation, and mania (Reinares et al., 2006). In the same study caregivers being interviewed discussed the fear they can experience with the variety of moods that can be displayed by their family member with bipolar disorder. Uncooperative behaviour/angry behaviour also caused stress for the above participants in addition to the helplessness they felt when their partners switched back and forth between all of the above behaviours/emotions (Reinares et al., 2006). As up to 48% of bipolar patients are not compliant with medication, this can create stress for caregivers as it makes moods even more unpredictable (Bauer, Gottfriedsen, Binder, Dobmeier, Cording, Hajak & Spiessl, 2011).

Another form of stress for caregivers is trying to ascertain whether or not they can hold their family member with bipolar disorder responsible for their actions while trying to figure if their family member is acting in a particular fashion because of the disorder, the medication, or just their regular personality. In one qualitative study a caregiver discussed this burden "It is your responsibility...although you are as mad as you are...I can take his illness into account, oh, look how pitiful he is, but he is still responsible for what he is doing" (van der Voort et al., 2009, p. 437). In their qualitative study, Travag and Kristoffersen (2008) interviewed eight spouses/cohabitants of people with bipolar disorder to discuss their experience of being a caregiver. One caregiver stated,

I knew what was important to us in our life, but at the same time I was totally without authority. Within his sick landscape, it was he who decided, and as I didn't have a name for what I saw, how was I to get others to understand me? I needed so badly to have somebody see me and the children. In the middle of this, I felt angry because he had hurt me, and I asked those who were treated him: Can't you get him to ask for forgiveness for all this craziness? I won't be treated like this! (Tranvag & Kristoffersen, 2008, p. 9)

Others take a different point of view "That is the illness and when I look at her and I see her lying asleep: This is the woman I love. I know she has got this disease, and I accept it because it is just there" (van der Voort et al., 2009, p. 438). Over 66% of individuals with bipolar disorder have at least one incident involving police for example, and this creates a lot of stress for caretakers that otherwise might not have interactions with the police (Dore & Romans, 2001). One caretaker noted: "she ran along the street taking her clothes off and the police were called" (Dore & Romans, 2001, p. 153). If the individual with bipolar disorder does something illegal, is violent, spends a huge amount of money or has an affair while manic, the caregiver has to figure out how they will deal with this and whether or not they can overcome these types of behaviours all while perhaps hoping that their family member may return to the person they were before the onset of the illness (Dore & Romans, 2001). "I think my main concern is that if he never gets back to some sort of fullness of life, in the sense of being able to reach some of the potential that he's got, that does concern me" (Maskill et al., 2010, p. 538).

Financial stress is another huge aspect of caring for a family member with bipolar disorder. In addition to the family member with bipolar disorder possibly spending huge sums of money while going through a period of mania "he spent up about \$5000 in a couple of weeks" (Dore & Romans, 2001, p. 152) there are also other costs associated with caring for families

members with bipolar disorder like private hospitals—“she spent three and a half months in a private hospital which cost us \$7000” (Dore & Romans, 2001, p. 152). In addition to the reduced income that most caregivers receive (discussed above) these costs can add tremendous stress to a caregivers’ lifestyle.

In order to find out how best to support caregivers to individuals with bipolar disorder van der Voort et al. (2009) conducted a qualitative study of interviews with caregivers of spouses with bipolar disorder to see what/if any burdens they carried and what sort of support these families needed (which will be covered in Chapter 4). The 15 spouses and ex-spouses interviewed had to speak Dutch, have lived/still currently living with their partner with bipolar disorder for at least five years, and be over the age of 21. In addition, the partner with bipolar disorder had to have had suffered from at least three manic/depressive episodes over the course of their lifetime and one in the last year. van der Voort et al. (2009) discovered that caregivers are trying to find the balance between self-effacement (putting the needs of others first) and self-fulfillment (putting one’s own needs first) when acting as caretakers. There is a lot of guilt and stress involved in this process and one risks burnout if they choose self-effacement. One spouse who was interviewed in the study above and who ended up divorced commented that she should have paid more attention to her own needs and that this may have saved her marriage (van der Voort et al., 2009). Other caregivers wrestled with trying to figure out if they could influence their family members’ behaviour and when they couldn’t they felt hopeless “he was so depressed all day, and after he was gone, I felt so sad...everything you try to do, it is of no use” (van der Voort et al., 2009, p. 438). Not feeling as though they could make a difference in their family members’ mood can lead to feelings of hopelessness and depression. Studies show that if the caregiver feels overburdened her or his chances of developing depression increases. If the

caregiver does become depressed this can have significant implications on both the caregiver and the family member with bipolar disorder (van der Voort, Goossens, & van der Bijl, 2007).

With regards to the medical care received, caretakers and their family members with bipolar disorder expressed in various studies (Elgie & MorrSELLi, 2007; Bowden, 2001) frustration at the amount of time it took to receive a correct diagnosis. This was a huge source of stress and confusion and left individuals wondering why certain behaviours were happening. Most caretakers felt that any professional help they did receive was aimed more at the individual with bipolar disorder than the caretakers. They also expressed trying to seek out professional medical help as yet another burden that resulted in feeling stressed out and unsure of how to properly help their family member with bipolar disorder (van der Voort et al., 2009). As a result of not feeling educated with regards to bipolar disorder, caretakers felt they were not adept at explaining the disorder to other family members/friends which sometimes resulted in hostile attitudes from family and friends regarding bipolar disorder and behaviours that can come along with it. This could lead the caregivers to feeling further isolated and alone with this burden (Elgie & Morselli, 2007). When caretakers did receive professional help, it could be a frustrating experience because even professionals didn't fully understand bipolar disorder:

They will say, 'oh he's not being compliant', that big bloody word, I hate it. And I said well he's not going to be compliant, you know that's part of his illness...he gets thrown out for being sick. You see it a lot with lots of clients. And they use the compliant thing and I think what a lot of crap. I mean if he was well enough to be compliant he wouldn't need their help, would he? (Maskill et al., 2010, p. 539)

While depressive episodes are very stressful for the caretaker as they worry about their loved one committing suicide, manic episodes are another form of stress for caretakers of family members

with bipolar disorder. In their study described above Maskill et al., (2010) had one participant who said,

I guess maybe when you think about manic depression you think the depression would be the worst because you know, you may be involved with suicide and that type of thing...and that is a fear, but it's almost worse the other way, that they're going to do something absolutely...and it's going to cause some mayhem if not to themselves to other people around them. (Maskill et. al, 2010, p. 539)

During manic episodes, caregivers have experienced “bizarre, disturbed, abusive, manipulative, aggressive and violent behaviour,” which left them feeling frightened, powerless, and at risk (Chang & Horrocks, 2006, p. 438). In the aforementioned qualitative study, Travag and Kristoffersen (2008) interviewed eight spouses/cohabitants of people with bipolar disorder. One participant explained the mania in their partner thusly:

his whole personality changed completely when the mania came. It was as though he was possessed by something alien. He ‘disappeared’ and ‘someone else’ took over, in a sense. He lost his sense of reality. It was so frightening because I didn’t understand what was happening. My brain was put out of action, had nothing to offer. I didn’t know what to do. I was just terribly frightened. (p. 8)

During manic episodes, the individual with bipolar disorder has no insight into their illness and can therefore see the caretaker in an oppositional role (Ogilvie, Morant, & Goodwin, 2005, p. 28). “Once he threw me on the floor and tried to butt my head.” Another caregiver said “He threatened me with a chain saw once,” and another caregiver said “She was about to stab me with a kitchen knife so I knocked her out” (Dore & Romans, 2001, pp. 149-150). The behaviours enacted during manic episodes can leave caregivers feeling stigmatized, which

creates even more stress (Perlick, Rosenheck, Clarkin, Maciejewski, Sirey, Struening & Link, 2004).

### **Stigma**

As a result of depressive and manic episodes and the behaviour that may come along with them, the caretaker of a person with bipolar disorder may feel stigma and shame for being associated with her or his family member. Caregivers may also experience social rejection (Gonzalez et al., 2007). As many people do not fully understand bipolar disorder caretakers can be blamed for their actions, “The family blamed me. They didn’t see him as ill—they saw me as putting him into the hospital. One of them wouldn’t speak to me for years” (Dore & Romans, 2001, p. 154). In their qualitative research study in the south of Sweden, Johsson, Skarsater, Wijk, and Danielson (2011) interviewed 17 spouses over the age of 18 who had a family member with bipolar disorder in order to see what the experience was like for them. One participant with a partner who has bipolar disorder said,

You become a little isolated more or less; you see, you have carried it around by yourself a lot, because with this type of illness, she can look totally normally among other people and no one notices anything, other than those closest to her. Like me, I see the signs and then at home she acts out everything and then pulls herself together when she’s away. (p. 32)

Caregivers for a female family member with bipolar disorder may feel more stigmatized by manic behaviours such as “hypersexuality, aggression, and risk-taking, because these traits are more socially acceptable in males” more so than caregivers for male family members (Gonzalez et al., 2007, p. 46). As a result of feeling stigmatized caregivers could suffer shame and embarrassment, which may lead to them avoiding talking about their family member’s condition

in order to save face and not have to explain, defend, or deal with misunderstandings or ignorance from other people (Chang & Horrocks, 2006).

### **Conclusion**

Being diagnosed with bipolar disorder may be devastating to both the individual and those closest to them. Having a family member with bipolar disorder can have positive implications but can also cause a breakdown of family functioning, and may be difficult for everyone involved (Chang et al., 2001; DelBello & Geller, 2001; Du Rocher et al., 2008).

Caretakers of individuals with bipolar disorder may be fearful of manic episodes and experience stigma as a result of having a family member who has bipolar disorder (Chang & Horrocks, 2006).

## ESSAY 2: CHILDREN OF PARENTS WITH BI-POLAR DISORDER

In this essay, a review of the literature of the experiences of children with parents who have bipolar disorder will be offered. As children who have parents with bipolar disorder are at greater risk of developing a wide range of psychopathology including mood disorders, attention deficit hyperactivity disorder, substance abuse, and anxiety disorders, it is important to heighten the awareness of these issues—not only for the parent but also for the children (DelBello & Geller, 2001; Birmaher, Axelson, Monk, Kalas, Goldstein, Hickey, Obreja, Ehmann, Iyengar, Shamseddeen, Kupfer & Brent, 2009). In the following chapter the psychological risk factors for children of individuals with bipolar disorder will be discussed, followed by firsthand accounts of children's experiences of growing up with a parent with bipolar disorder in hopes of understanding how early intervention of mood disorders can be detected in order for children to receive the support they need.

### **Children of Parents With Bipolar Disorder: Risk Factors**

In order to best understand how to support and provide early interventions for children of parents with bipolar disorder who are at risk for psychological disorders, we must first understand their risk factors. Children with parents with bipolar disorder are at higher risk for developing psychiatric disorders (Birmaher et al., 2009; Hillegers, Reichart, Wals, Verhulst, Ormel & Nolen), poor interpersonal functioning (Ostiguy, Ellenbogen & Hodgins, 2012), high levels of disturbance (Calam, Jones, Sanders, Dempsey & Sadhnani, 2012), behavioural disinhibition (Hirshfeld-Becker, Miederman, Henin, Faraone, Cayton & Rosenbaum, 2006), thought problems (Klimes-Dougan, Desjardins, James, Narayan, Long, Cullen, Gold & Martinez, 2013), sensitivity to stress (Ostiguy, Ellenbogen, Walker, Walker & Hodgins, 2011), and negative family milieu (Hammen, 2002).

## **Mood Disorders**

It is imperative for psychiatrists to identify and create a treatment plan for person's diagnosed with bipolar disorder earlier in life in hopes of being able to prevent negative outcomes later in life such as poor social functioning and suicide in extreme cases (Birmaher et al., 2009). Treating bipolar disorder early on may also decrease the negative effects on the family unit that can be experienced when a person with bipolar disorder has children. In their Medline search conducted in order to identify studies that examined child and adolescent offspring of parents with bipolar disorder from 1966-2000, 17 studies assessing psychopathology in children and adolescents were found (DelBello & Geller, 2001). Studies were excluded if they also discussed major depressive disorder. What they found was that overall, children of parents with bipolar disorder were at increased risk for major depressive disorder, substance use, conduct disorder, and oppositional defiant and anxiety disorders when compared to children with parents without bipolar disorder. Rates of mood disorders were five to 67% in children who had a parent with bipolar disorder compared to zero to 38% of children who had parents without bipolar disorder. DelBello and Geller (2001) also discussed Lapalme and colleagues' meta-analysis of child and adult offspring of parents with bipolar disorder who found that 52% of offspring of parents with bipolar disorder had a mental disorder compared to 29% of offspring from parents without bipolar disorder, stating that offspring of parents with bipolar disorder are 2.7 times more likely to develop a wide range of psychopathology than offspring of parents without bipolar disorder. In addition, offspring of parents who had bipolar disorder were four times more likely to develop an affective spectrum disorder, including bipolar spectrum and unipolar disorders (Lapalme, Hodgins & LaRoche, 1997). It should be noted that in their

Medline search, DelBello and Gellar (2001) did not distinguish between Bipolar I and Bipolar II, for this reason their results may not be transferable.

### **Thought Problems**

Klimes-Dougan et al. (2013) designed a study with the purpose of evaluating the developmental progression of thought problems (such as obsessive, anxious, or depressed thoughts) within families with parents with a diagnosis of bipolar disorder. Their study spanned 15 years and included offspring of 98 families with parents with bipolar disorder, unipolar depression, or no diagnosis. Survival analysis showed that the offspring of parents with bipolar disorder had the highest probability of developing thought problems over time. They discussed that thought problems are likely to disrupt the path of normal development both in childhood and development. Specifically, they discussed

social and cognitive development in childhood and adolescence increasingly requires youths to more accurately understand logical relations and rules for interacting with the world around them by generating and testing hypotheses about stimuli in the environment against their established knowledge. Impairments in reality testing likely undermine the validity of previously formed conclusions, which are necessary for successful negotiation of the social world. (Klimes-Dougan et al., 2013, p. 1080)

They also discussed that children of mothers with affective disorders “exhibit atypical thoughts and behaviors at a time in development when significant refinements in abstract reasoning, reality testing, social cognition, and executive functions abilities are taking place in typically developing children” (Klimes-Dougan et al., 2013, p. 1086) and therefore suggested that specific attention needs to be paid to adolescents with parents who have affective disorders. Limitations

of this study include a small sample size and a longer timeframe might have been more beneficial.

### **Disturbance/Poor Interpersonal Functioning**

Calam et al. (2012) recruited 48 parents of which one of the parents was diagnosed with bipolar disorder in an online study in order to have the parents assess their children's emotional and behavioural difficulties. The majority of parents described that their children had "high levels of difficulty in adjustment" (p. 432), and more specifically described their children as having high levels of anxiety, depression, conduct problems, and hyperactivity. Parents also reported their children as having considerable impairment in social functioning. Calam et al. (2012) concluded that families are likely to benefit from early interventions in order to help the parents with their children. Some limitations to this study include that the study was done online, which may exclude parents with bipolar disorder that do not have access to a computer as well as the advertisements used to recruit participants were only posted in a select area again limiting the diversity in participants.

Similar results were found in Ostiguy et al.'s (2012) 10 year study of children with parents with bipolar disorder versus children of parents without bipolar disorder with regards to the parents' levels of high neuroticism and low agreeableness. The definition of neuroticism used was "a personality trait characterized by a propensity to experience negative emotions such as anger, sadness, guilt, and irritability" (p. 573). The children were first interviewed in middle school and again 10 years later. They concluded an "intergenerational transmission of risk whereby high neuroticism and low agreeableness in parents" was associated with behavioural problems in middle school and poor interpersonal functioning 10 years later (p. 573). Their definition of poor interpersonal functioning included difficulties creating and maintaining

satisfying relationships with family, peers, and romantic partners and possibly an affective disorder down the road.

They further postulated that

the child that inherits these genes associated with mood disorders inherits a tendency to react emotionally to stresses and daily hassles. This tendency is promoted by being raised by one or two parents with high levels of neuroticism who themselves display a pattern of overreactivity to daily life events and ineffective coping with stress. (p. 574)

Essentially the child grows up in a stressful and chaotic environment that neglects to teach the child appropriate skills for handling life's stresses.

### **Disinhibition**

Hirshfeld-Becker et al. (2006) completed a study of 216 parents identified as having bipolar disorder or no disorders and 278 children ranging in age from two to six years of age in order to assess the temperament of the children. Temperamental assessments were conducted in the Harvard Infant Study laboratory. The evaluations of the children were completed when the children were aged two, and then four, and then six years of age. The children were classified as showing behavioural disinhibition if they approached unfamiliar stimuli (novelty-seeking) or had disinhibition of speech or action (impulsivity). They concluded that the rate of behavioural disinhibition was significantly higher in children of parents with bipolar disorder, suggesting a familial link between the parents with bipolar disorder and behavioural disinhibition in children.

### **Sensitivity to Stress**

Ostiguy et al. (2011) set out to determine whether interpersonal chronic and episodic stress moderated the relationship between cortisol levels in the natural environment and risk status (by having a parent with bipolar disorder). In the first phase of their longitudinal study,

parents, their spouses, and children were recruited from psychiatric and support groups in Quebec, Canada, to identify parents with bipolar disorder. Then comparison groups (without bipolar disorder) were recruited from the same neighbourhoods as the parents with bipolar disorder. Then 10 years later, 123 offspring participated in a clinical reassessment, cortisol sampling, and an information processing protocol.

The study had three main findings: Firstly, the offspring of parents with bipolar disorder had higher levels of daytime cortisol than children with parents without bipolar disorder. Secondly, they found that the offspring of those with bipolar disorder had higher levels of chronic stress, which predicted higher levels of cortisol. Thirdly, the children of parents with bipolar disorder who experienced higher levels of interpersonal chronic stress exhibited higher hypothalamic-pituitary-adrenal axis reactivity after waking up than the offspring who reported low levels of interpersonal chronic stress. In children with parents without bipolar disorder, no association between chronic stress and cortisol levels was found. This suggests that children of parents with bipolar disorder are physiologically more sensitive to stress in the natural environment than children with parents who do not have bipolar disorder. They suggested this may be because the children were raised in chaotic family environments in which parents didn't model effective skills for coping with stress (Ostiguy et al., 2011). There were some limitations to this study, including the age sampling being 14-28 years of age therefore this study may not be transferable.

### **Negative Family Milieu**

As bipolar disorder is made up of both manic and depressed episodes, it is important to discuss the impact that depression may have on children of bipolar parents. Hammen (2002) discussed that children of parents that have depression may “inherit biological predispositions to

mood disorders but also a family milieu that may be highly challenging and stressful” (p. 175). Hammen goes on to discuss that the child is exposed not only to the symptoms of the parents’ depression, but also the stressful conditions that can come along with this like financial, occupational, and marital difficulties. Both the parent and child can experience elevated rates of episodic stress as a result of these difficulties. When discussing stress, Hammen describes four specific types of stress a child with a depressed parent may feel. Having a parent who is depressed is difficult on a child as they may feel helpless, children may need to take on a caregiver’s role, which may also be stressful and will be discussed in the next section. Lastly, the child may have her or his own stresses outside of the parent’s depression and be struggling to handle this in addition to their parents’ depression. As a result of the above stressors, the parent child relationship can suffer and the child receives poor modelling skills of parenting/stress management (Hammon, 2002).

### **Children’s Experience of Growing up with a Parent with Bipolar Disorder**

In addition to the genetic risk factors that children of parents with bipolar disorder are up against, having a parent who may switch between being manic, neglectful, depressed, and unpredictable may have a powerful influence on a child’s psyche (Chang, Blasey, Ketter & Steiner, 2001). For this reason, providing support to children of individuals with bipolar disorder should become standard care in hospital settings (Bauer, Spiessel & Helmbrecht, 2015).

In order to understand the experiences of children who grew up with a parent with bipolar disorder it is important to not only discuss what the research states regarding genetic predispositions, as addressed above, but also find out from the children the kind of experiences they had growing up, and the types of help they would have found helpful so that we can better support children in this situation in the future. The following section will include first-hand

accounts of children who grew up with a parent with bipolar disorder. The accounts are categorized into themes of experiences the children discussed having. These are direct quotes from various sources in which children with parents who have bipolar disorder discussed their experiences.

### **Positive Experiences Resulting from Having a Parent with Bipolar Disorder**

Georgina wrote about her experiences of having a parent with bipolar disorder between the ages of 17 and 19. She discussed the positive outcomes of her relationship with her mom:

For about three years Mum remained more stable with the exception of a few short episodes of being high or low. My mum's bad patches when she's unwell can last a day, a few days, weeks, even months, but it makes us appreciate her even more when she's well, and when she has gotten over her bad patch, she is well for a much longer period of time. (Aiken, 2010, p. 3)

Twenty-year-old David stated,

Having a parent with bipolar I feel that I have matured a lot more quickly than I was supposed to. But I'm not complaining as I am happy with who I am. I feel that there are times when I help Mum out, by telling her she's going too high, that she needs to calm down and go to bed or just a hug and a kiss when she's feeling low. I'm not my mother's carer as she is a very "high functioning" sufferer of bipolar. She's a great mother to me. The caring role goes both way. I will look after her if she is ill and she looks after me as her son. I guess in a way I just see my mum as a very good friend rather than a mother sometimes. (Aiken, 2010, p. 7)

Nine-year-old Bethan discussed being able to spend more time with her mom when she was depressed:

When she is sad, she cries a lot, blows her nose and her face goes bright red, which is funny. I like it better when she is sad and I can cuddle her and kiss her, because when she is busy, she does lot of chores that don't need doing, and I can't cuddle her and make her feel better. When she is busy, she does not spend so much time with me. (Aiken, 2010, p. 9)

There were also negative affects the children discussed such as taking on more responsibility.

### **Taking on More Responsibility**

One of the major themes that emerged from the children was feeling like they had to take on certain responsibilities as a result of their parents' bipolar disorder. When speaking of her mom having bipolar disorder and how it affected her as a child, Koulla aged 43 stated,

My life changed too. I became my mother's mother. I had to take care of my little brother, help my dad, cook and do all the household chores. I would also have to encourage Mum to have a bath, change her clothes and eat. (Aiken, 2010, p. 16)

Twelve-year-old Hannah echoed a similar statement "Sometimes I feel more like my mum's parent because, at times, I have to look after her and my brother. I have to make tea and things like that" (Aiken, 2010, p. 6). Hannah also stated, "I have to do lots of jobs to help and it gets on my nerves and then I get upset and shout at Mum which then makes her far worse. Life is hard but we do have good times when Mum is well" (Aiken, 2010, p. 6).

Eleven-year-old Jack also discussed his increased responsibility stating,

I feel like I have run around the world a thousand times because me and my sister have to help my mum because she is poorly sometimes. She gets very tired. I feel so sad at times but I am a person who tries to keep my feelings inside. (Aiken, 2010, p. 8)

Fifteen-year-old James said,

Over the past year, I have found myself taking charge of situations when mum is either going high or low. I had to come home early from school last week, to look after her, as she was very down, and could not be left on her own. My dad was at work and her close friends were all out. That had never happened before. I cuddled her and listened to her while she cried. I gave her some reassurance that she said really helped her. (Aiken, 2010, p. 8)

Presley (2009) interviewed children of parents who had bipolar disorder in order to get their perspective and also found the children discussed feeling more responsibility as a result of their parent's illness. Thirty-eight-year old Bridget, for example, began to take emotional responsibility for her brothers before seventh grade:

I already knew that mom wasn't in control, so I was going to have to be in control, so... I used to really, worry about my brothers walking home from school 'cause she would freak out about that. Somebody was going to kidnap 'em, somebody is going to take 'em, y'know. And I remember one time really having a huge amount of anxiety because one of my little brothers wasn't home from school yet. And I was not in the 8th grade. I must have been younger, and just feeling like if he didn't then it was me, I should have ... I already was starting to feel like I had to take control of that. I was ...very upset that he wasn't home. And I thought something was horrible was going to happen to him. But looking at it...She was acting that way and pacing and... acting weird. (Presley, 2009, p. 132)

And Alice aged 36 remembered,

I do remember there were times when my mom did housework, she slept a lot. She would get up and make dinner. I remember coming home from school and watching TV and she

would be sleeping on the couch. She slept quite a bit... I didn't really think about it because I didn't know differently. As far as I can remember, she always slept a lot and cooked. The housework me and my siblings did most of the time. Well, I felt like I was the mother and she was the child then, and having to take over the role, even though I felt like I was a mother when I was littler. But then, it was even more pronounced. I'm having to lead her around and be like the mother to her... and she hasn't really, you know, been my mother. There was resentment...and then, maybe I didn't understand everything back then, that she couldn't help it... rebelled against responsibility all through life, but had it thrust upon me [laughs]. (Presley, 2009, p. 132)

In addition to feeling as if they had to take on more responsibility because of their parents' illness, children also worried about getting bipolar disorder themselves.

### **Fear of Developing Bipolar Disorder**

Hannah, a 12 year old said, "I do worry a bit about developing bipolar myself because I wouldn't want to be crying all the time, and it seems as if my mum is always tired. I want to be active" (Aiken, 2010, p. 6). Koulla aged 43 said,

Do I fear developing bipolar myself? Yes, I do have this fear and am sure my brothers share the same feelings. If I'm ever feeling low, I make sure I pick myself up; I change any negative thoughts to positive ones. I share my feeling or worries and speak to my close friends or immediate family. (Aiken, 2010, p. 16)

The children also discussed how they felt about the ups of downs of their parent's bipolar disorder.

### **Inconsistent Parenting**

Forty-six-year-old Sandy, who had a parent with bipolar disorder growing up stated,

It's the inconsistency that gets to you the most. If she were consistently down or consistently high, it would have been easier. Like my dad—he was difficult to live with but at least I knew where I stood with him because he was consistently grumpy and sullen. Not knowing what to expect when you walk or skip through the front door—happy or sad, warm or cold—makes you anxious and fearful. (Aiken, 2010, p.14)

Nineteen-year-old Georgina stated,

When my mum sleeps less, eats less, has more energy and spends more money, it's usually a sign that she's going high. The symptoms of both mania and depression are quite distinct, although I often mistake little things that are nothing for symptoms of depression or mania. When my mum's manic, it's as if someone has pressed a fast forward button on her and she has super powers to do the impossible, which is scary, because she really does believe she can do anything, and I feel like everything needs to be out of her reach. When she is depressed she stays in bed most of the time, or cries to friends on the phone. I get very frustrated when she's depressed because I want to be able to do something to change the way she is feeling but I know I can't. (Aiken, 2010, p. 3)

Georgina also stated “I'll often say “Is this going to make you ill?” as I need the reassurance that she is okay” (Aiken, 2010, p. 4).

Fifteen-year-old Tasha Aiken said,

When my mum is high, I feel very weird and controlling, but I don't like that because I can't control her. When she is low I do feel like *her* mum and I really don't like it because it does upset me, and people say I need to understand her illness even though I

do, but people don't understand that it does still upset me however much I understand her. (Aiken, 2010, p. 4)

### **Isolating Themselves Because of Parents Bipolar Disorder**

Tasha Aiken explained,

When she is really ill, I don't usually talk to friends because they all say the same thing saying, "Aww, I hope she gets better." They don't understand as much as some people and they also say they know how it feels which annoys me because they really don't because none of their mums are like mine. Most of my friends just think it is like a broken leg or arm and it will heal, and they don't understand that it won't. (Aiken, 2010, p. 5)

Twelve-year-old Hannah said "Being the older child makes life a bit harder when your mum suffers from bipolar. Sometimes you can feel stuck in the dark, because other children are playing out and we can't because Mum is in bed, so we are inside bored" (Aiken, 2010, p. 6).

The children also discussed the effects having a parent with bipolar disorder had on them as will be discussed below.

### **Effects Felt by Children as a Result of Having a Parent with Bipolar Disorder**

Georgina (19) discussed the effects of her mom's illness on her school schedule:

Because of the problems at home, my school work was terrible and I was at school for no more than three days a week due to upset and stress. I hated school and although I had wanted to be there, I didn't any more. (Aiken, 2010, p. 2)

Sandy, who remembered to her childhood, talked about the anxiety she felt as a result of having a parent with bipolar disorder:

I didn't know my mother was ill or suffering. I only know how I felt. I felt disappointed and frustrated which manifested into fear and anxiety. It's the inconsistency that gets to you. The never knowing what you'll find when you get home from school. On a really good day there would be music playing or the TV on or both. ...On a bad day the house would be cold, silent. She'd be asleep on the settee, pinchy on, paper hanky stuffed in her hand, swollen eyes. ...My fears and anxieties grew as I grew because I didn't quite trust her with things that I thought were important. (Aiken, 2010, p. 1)

Twelve year old Hannah discussed her feelings of helplessness and not understanding her mom's illness "Mum suffers from more of the depressive side, where she just cries and goes up to bed to sleep. I feel bored and lonely at these times. I want to understand but I just can't get my head around it. Sometimes I don't know what I can do to help" (Aiken, 2010, p.6). Debbie stated her sadness and compassion for her dad and his lost personality when bipolar affected it:

Until you have seen someone with actual real depression you cannot even begin to comprehend it—it is like the soul has been sucked out of them and all that is left is a shell with staring eyes. My mum and I always say there could not have been a more torturous illness for my dad to get. His confidence went, his sparkle went, his whole personality changed. (Aiken, 2010, p. 11)

The children being interviewed also discussed the ways they coped with their parent's bipolar disorder, which will be discussed in the next section.

### **Ways Children Coped with their Parents Bipolar Disorder**

The children discussed above used a variety of methods to get through the challenging times that bipolar disorder imposed on their lives. In order to cope with her mom's illness Tasha said,

I used to have a counsellor in my old school and I found her very helpful I talked to my auntie or my dad a lot if it is upsetting me. When my mum gave me a lot of information about bipolar I found it helpful and it made me understand a lot better and she explained that she isn't as bad as ever committing suicide or anything as bad as that, but I have seen the worst of her. I sometimes talk to my sister because I find that helpful because we are both in exactly the same position. I know she has found things very hard and I want her to talk to me even if I can't help, because I am out with her a lot and I want her to be able to tell me anything. (Aiken, 2010, p. 5)

Hannah also reaches out to other for help "I have support from a young carers group. I also have the same friends and family as my mum, and they all say I can talk to them if I'm worried and I do. Also I talk to her nurse" (Aiken, 2010, p.6).

David tried to not take on his mom as a project he had to fix and used his friends as supports when his mother was ill:

I don't take it on my own shoulders to "fix Mum." But when she does have an episode either way, I just do my part around the house, whether it's cook for the kids or tidy up the lounge. I usually just do what I can rather than take on impossible tasks.

[Later down the page]...I don't have any formal support like care workers or anything like that as I don't feel it necessary. My parents understand that I sometimes need to get out and go and chill at a mate's house. So for support I have my family and friends and that's all I need. (Aiken, 2010, p. 7)

And Georgina (19) stated that she has learned to talk about her mother's illness to help her cope with it "I've learnt to know that I have to talk about my mum's bipolar if I'm upset, in order to

feel better, but I don't feel comfortable talking about her being unwell as I feel as if I'm being a pain" (Aiken, 2010, p. 4).

Based on these children's experiences growing up with a parent with bipolar disorder, it seems to be apparent that more support is needed for these children in order to help them cope with their parents' illness (Bauer et al., 2015). Various forms of support that may be useful include offering children psychoeducation regarding the positive and negative effects of bipolar disorder on the family unit, empowerment with regards to extra household duties that they may have to carry out as a result of having a parent with bipolar disorder and counselling/support with their emotions (Bauer et al., 2015). Further recommendations for support will be given in chapter four.

### **Conclusion**

Having a parent with bipolar disorder may increase a child's disposition to a variety of mood disorders and other mental health related issues in addition to potentially negatively affect her or his social functioning. While parents with bipolar disorder should receive support and treatment, it appears that their families and children also need support in order to better understand the parent's illness. Early intervention and support of children of parents with bipolar disorder may improve their overall functioning and lessen the chances of developing mental health related issues (Bauer et al., 2015).

### ESSAY 3: HOW TO PROVIDE BETTER SUPPORT FOR FAMILY MEMBERS CARING FOR LOVED ONES WITH BI-POLAR DISORDER

In this chapter, a review of the literature of the experiences of caretakers for bipolar individuals interacting with various medical models around the world will be offered along with the consequences of not having support in place for these caregivers. Multiple studies have discussed the negative impact of being a caregiver and not receiving the necessary support from medical professionals (Maskill, Crowe, Luty & Joye, 2010; Bowden, 2001; Baronet, 2001). In the following chapter the implications of caregivers not receiving the necessary support will be discussed along with the negative aspects of caregiving while having challenging interactions with medical institutions. This will be followed by a discussion of recommendations for caregivers and medical models as well as recommendations for caregivers.

#### **Implications of Not Having Enough Support for Caregivers**

In addition to the implications on caregivers' health and stress levels as discussed in Essay 1, other implications of being a caregiver to a family member with bipolar disorder also need to be discussed. The financial implications for families but also society as a whole when treating bipolar disorder are substantial. As stated in Essay 1, worldwide, bipolar disorder is the sixth leading cause of disability (WHO, 2001). In 1991, the US National Institute of Mental Health completed a study that estimated the costs to US society of bipolar disorder at \$45 billion dollars annually and \$38 billion was associated with indirect costs, for example lost productivity on the part of the caretaker and the individual with bipolar disorder when work hours were reduced in order to cope with the health of the family (Wyatt & Henter, as cited in Ogilvie, Morant & Goodwin, 2006). Dore and Romans (2001) discussed the extra costs that families affected by bipolar disorder spend by supplementing lost incomes, private hospitals, in addition

to recovering from spending sprees that may sometimes occur when an individual is going through a manic episode. In addition to financial implications of bipolar disorder felt by families and society as a whole, a great deal of stress and burden is felt by caretakers of those with bipolar disorder when encountering the medical model and medical professionals.

### **Over Involvement of Caregivers: A Move Away from Institutions to Home Care**

As the shift occurred in the last 20-30 years from using psychiatric institutions as a way for treating mental health issues such as bipolar disorder towards family based care, the role of informal caretaker has now been taken on by families, spouses, and children of those with bipolar disorder (van der Voort, Goossens, & van der Bijl, 2009). Informal caregivers are essential in the well-being of those with mental health issues such as bipolar disorder, yet policy makers and service providers often take their assistance and collaboration as a given while forgetting they also need to be supported. Unfortunately, few resources are allocated for caregivers as the majority of the attention is focussed on the individual with bipolar disorder (Ogilvie et al., 2005).

As a result of the lack of funding/services/information available for the families of those with bipolar disorder, the family unit can suffer. In a study by Perlick, Rosenheck, Clarkin, Maciejewski, Sirey, Struening and Link (2004) trying to evaluate the direct and indirect effects of family burden and affective response on medication adherence among patients with bipolar disorder, 101 pairs of patients (identified as having bipolar disorder) with their family caregivers were studied for 15 months and assessed within two weeks of either discharge from the index inpatients' admission at a university-affiliated hospital or initiation of outpatient treatment. In addition, the patients and their caregivers were assessed seven and 15 months after the baseline assessment (Perlick et al., 2004). This study suggested that families who reported feeling high

levels of stress and burden, displayed higher levels of emotional over-involvement. The study found that patients with bipolar disorder with caretakers who were overinvolved were less likely to adhere to medication and as a result the patients with bipolar disorder were more likely to have a major episode of either depression or mania over time. This seems to illustrate the importance of offering supports for caregivers as the impact of the stress felt by the caregiver can also impact the individual with bipolar disorder. It should be noted that because of the restrictions of age and the specific location of the study, the results of this study may not be transferable to the general population.

### **Problems with the Current Methods of Treating Bipolar Disorder**

In order to improve caregivers' interactions with the medical system, we must first understand the problems that have arisen and the burdens that caregivers have experienced. Identifying problems with the current way in which bipolar disorder is treated by medical professionals can lessen caregivers' burdens in the future and help individuals with bipolar disorder live a more supported and balanced life (Renaires, Vieta, Colom, Martinez-Aran, Torrent, Comes, Goikolea, Benabarre, Daban & Sanchez-Moreno, 2006).

### **Misdiagnosing Bipolar Disorder**

Misdiagnosing is common when it comes to bipolar disorder. Bowden (2001) wrote an article in order to give health-care professionals strategies to reduce misdiagnosis of bipolar disorder (which was the name of the article). Bowden discussed that the criteria outlined in the DSM (American Psychiatric Association, 2013) that an individual needs to have met a specific number of both manic and depressive episodes. Bowden (2001) describes this as being problematic for a number of reasons. Individuals usually don't see a psychiatrist if they are manic as they are usually feeling pretty good (manic episodes are euphoric for many

individuals) but may seek out help if they are feeling depressed. Many persons underreport manic episodes for the reasons stated above. The younger the individual who visits the psychiatrists/psychologists/health-care professionals' office, the more likely the chance that she or he has yet to have experienced a manic episode as depression is usually experienced first in individuals with bipolar disorder. This can lead to a diagnosis of major depressive disorder as the individual has not yet experienced a manic episode. Also, in order to diagnose an individual with bipolar disorder, her or his manic episodes need to last at least one week according to the most up to date DSM-5 (when Bowden wrote the above article the requirement according to the DSM-4 for the manic episode was four days) (American Psychiatric Association, 2013). Bowden discussed that in his experience it was rare that a manic episode lasted four days, which resulted in a diagnosis of major depressive disorder instead of bipolar disorder. Being diagnosed as having major depressive disorder when an individual is actually suffering from bipolar disorder is problematic as the drugs that would be prescribed for major depressive disorder would exacerbate hypomania, mania, or cycling between the two, which could have severe consequences to the individual and her or his family, as discussed in Essay 1 (Bowden, 2001). Additionally, as a result of the wrong diagnosis, treatments including mood stabilizers and counselling would be delayed.

### **Early Release from Hospitals**

Caregivers of family members with bipolar disorder also discussed frustration because they feel psychiatric hospitals can release their loved ones even though they are not better:

He ends up on the street so I pick him up. Because I think if you don't he's not going to get to eat, to sleep, he will just get manic, he hasn't got any meds, he gets beaten up, he gets used for money by others that are street wise. (Maskill et al., 2010, p. 539)

Individuals with bipolar disorder also express this frustration. Logan (2013) discussed being discharged from the hospital and feeling like she and many others “mistook the word ‘discharge’ for ‘recovery’ and had to come home to her children asking ‘why did they let you out if you’re not better?’” (p. 3).

### **Not Treating the Whole Person**

Logan (2013) also expressed her frustration with being treated as a person with a disorder with the goal of symptom reduction instead of a whole human being. While she was worrying about who she was and who she would become as a result of being diagnosed with bipolar disorder, her doctors only seemed to care about whether or not she was improving from a medical standpoint with regards to her symptoms. Logan stated she wanted to be treated as a person not a patient:

The moment the psych-unit doors locked behind me, I was stripped of my identity as wife, mother, teacher and writer and transformed into patient, room number and diagnosis. I couldn’t open a refrigerator without permission. If I were on suicide watch, I had to ask before going to the bathroom. I was told when to sleep and when to wake, when to eat and when to go to group. (Logan, 2013, p. 2)

Over the years, I’ve talked to clinicians about why the self is rarely mentioned in treating patients who suffer from mental illness that damage their sense of who they are. If anything, it seems that psychiatry is moving away from a model in which the self could be discussed. For many psychiatrists, mental disorders are medical problems to be treated with medications, and a patient’s crisis of self is not very likely to come up in a 15-minute session with a psychopharmacologist. (Logan, 2013, p. 6)

The lack of care for the impact that bipolar disorder may have on one's psyche should also be addressed by health-care professionals (Logan, 2013). Other ways of treating people with bipolar disorder are emerging however, including psychologists using talk based therapy to help people "recognize that their mental trauma is part of their life, but shouldn't dominate it" (Fisher as cited in Logan, 2013, p. 6).

### **Recommendations to Improve Relationships Between Caregivers and Health Professionals/Counsellors**

In their qualitative study, Travag and Kristoffersen (2008) interviewed eight spouses/cohabitants of people with bipolar disorder to discuss their experience of being a caregiver. Based on the experiences of the participants of this study, Travag and Kristoffersen made recommendations for improvements in treating caretakers of family members with bipolar disorder. Their recommendations included that health-care workers be empathic and offer care and information to caregivers in order to reduce their burden and also to understand that these caretakers may have felt they have been overlooked and perhaps turned away when previously dealing with health-care professionals. Health-care professionals could also use psychoeducation/meaningful information in order to help the caregiver understand how bipolar disorder may affect their loved one in hopes they can mentally prepare for potential behaviours in order to reduce the caregivers sense of powerlessness. Health-care professionals could also invite caregivers to discuss their current troubles and thoughts about the future and offer support. Health care professionals could help the caregiver come to terms with stigma they may feel as a result of having a family member with bipolar disorder, and also discuss the tendency to isolate one's self because of this stigma. Health-care professionals could also explain the importance of self-care to the caregiver, helping caregivers to see the importance of taking care of themselves

too. The overarching aim of this qualitative study was to offer support to the caregivers and help normalize how the caregiver may be feeling (Travag & Kristoffersen, 2008). Baronet (2003) advocated for full inclusion of caregivers in medical appointments, group sessions, and treatment meetings. Three-way communication between the caregivers, medical professionals, and the individual with bipolar disorder was also recommended.

In their qualitative research study in the South of Sweden, Jonsson, Skarsater, Wijk, and Danielson (2011) interviewed 17 spouses over the age of 18 who had a family member with bipolar disorder in order to see what the experience was like for them. After reviewing their results, one of their main recommendations was for health-care professionals to have family sessions and within these encourage caregivers to maintain balance in their life and their relationships and to try to reduce feelings of guilt and responsibility that caretakers may feel. They also emphasized the “importance of hope as central” for the future life of caregivers (p. 34).

In order to improve the relationship between caregivers and medical professionals, Maskill et al. (2010) suggested that medical professionals have a non-judgemental and non-critical disposition towards caregivers and their loved ones, see the uniqueness in every family, and be honest with them—letting them know that bipolar disorder is incurable, but also allowing “room for hope” (Maskill et al., 2010, p. 541).

Gonzalez et al. (2007) interviewed 500 caregivers of individuals with bipolar disorder and concluded that interventions were needed at the community level that would decrease the level of stigma of bipolar disorder and serve as social support for families. It was also recommended that health-care professionals strongly work on helping to improve caregivers’ social support both in quality and quantity.

As a counsellor working with a caretaker of an individual with bipolar disorder, much of the above recommendations apply, it is important to treat each person as an individual, with compassion, and also be able to offer support and resources so the caretaker does not feel alone.

In order to decrease misdiagnoses of depression instead of bipolar disorder, Bowden (2001) suggested psychiatrists/other health-care professionals ask individuals whether they have noted hypomanic symptoms immediately before or after a period of depression. He also recommended asking the individual if family or friends have mentioned or commented on any symptoms to see if there are behaviours that others are seeing which might not be apparent the the individual with bipolar disorder. Lastly, Bowden recommended speaking with a close family friend or family member if possible during the intital assessment and continuing treatment to get another perspective on the individual's condition (Bowden, 2001).

### **Recommendations for Caregivers**

In their literature review covering the burden and coping skills needed by caregivers to individuals with bipolar disorder, Van der Voort, Goossens, and Van Der Bijl (2007) discussed numerous recommendations for caregivers. They emphasized the importance of knowing how to contact the health-care worker involved in emergency scenarios, for instance when hospitalization is needed. Caregivers should also have access to professional health-care workers if information or support is needed. Being kept up to date from health-care professionals regarding medications and treatment plans was also helpful for caregivers and advocating for oneself may be necessary through this process.

Perlick, Miklowitz, Lopez, Chou, Kalvin, Adzhiashvilli, and Aronsn (2010) designed a study where 46 caregivers of individuals with bipolar disorder experiencing depression either received 12-15 family-focussed, cognitive behavioural interviews designed to give caregivers

skills and manage stress, or eight-12 health education sessions via videotape. The caregivers in the first group experienced a significant reduction in depressive symptoms and improvement in health behaviours compared to the caregivers who watched the videotaped educational health sessions (Perlick et al., 2010). It should be noted that the caregivers in the first group received almost twice the number of sessions than the caregivers in the second group therefore these findings may not be transferable.

Berk, Jorm, Kelly, Dodd, and Berk (2011) used the Delphi method to find a consensus between international expert panels of 45 caregivers, 47 consumers, and 51 clinicians regarding what information should be given as a guideline to caregivers of individuals with bipolar disorder. The Delphi method allows stakeholders in various geographical regions to contribute their views privately at a convenient time. As this is a private process allotting more time for personal reflection, participants may express their opinions without feeling pressured by other group members as may happen in a live meeting. Expert participants are given a series of statements in which they rate the extent of their agreement, then are given statistical summaries of the results of the group ratings and their own ratings, followed by another round of rating. The statements are then narrowed down to those which have considerable consensus (Berk et al., 2011). It was recommended that caregivers find a balance between being a caretaker and a family member, suggesting that if one constantly remains in the caretaking role, then this can cause more stress and strain (Berk et al., 2011). If possible the caregiver should engage with their loved one in ways that are outside of the illness and where the person with bipolar disorder can also give back to the relationship (Berk et al., 2011). The caregiver should attempt to lead a healthy lifestyle and participate in activities outside of their caretaking role (Berk et al., 2011). It was also recommended that preventative actions could be taken in order to reduce the possibility

of negative circumstances, for example, the caregiver could look after their family members' credit cards to avoid overspending during a manic episode (Berk et al., 2011). Self-care by the caregiver was also highly recommended, meaning the caregiver takes time to do things they love and take care of themselves physically and mentally (Berk et al., 2011).

### **Conclusion**

As a result of moving away from institutionalized care over the last 20-30 years, family members are now the main caretakers for family members with bipolar disorder (Cuijpers & Stam, 2000). Caretakers of individuals with bipolar disorder may experience stress as a result of interacting with the medical professionals and the demands of helping their loved one through the challenges of this disorder. There are various ways in which their burdens can be lessened such as participating in self-care activities, having connections and support outside of being a caretaker, and seeking out information as to how to best support their loved one with bipolar disorder (Van der Voort, Goossens & Van Der Bijl, 2007; Berk, Jorm, Kelly, Dodd & Berk, 2011). Finding professional help that is non-judgmental, compassionate, and supportive is important in order to lessen the burden on both the caretaker and the individual with bipolar disorder (Maskill et al., 2010).

## CHAPTER 5: CONCLUSION

Bipolar disorder like many other so called mental disorders can be experienced on a spectrum and in many different ways. It is possible that a person with bipolar disorder may experience certain crises throughout the illness in the form of manic or depressive episodes, although many people enjoy many healthy and stable days in between episodes. When episodes do occur, however, it may create stress on families living and caretaking for an individual with bipolar disorder (Maskill, Crowe, Luty, & Joyce, 2010; Baronet, 2003; Change & Horrocks, 2006). Caretakers of bipolar disorder may also experience stress as a result of interactions with medical professionals (Ogilvie, Morant & Goodwin, 2006; Perlick, Rosenheck, Clarkin, Maciejewski, Sirey, Struening & Link, 2004). It may also be stressful to have a parent with bipolar disorder and children in this circumstance have increased risk of psychopathology (Hillegers, Reichart, Wals, Verhulst, Ormel & Nolen, 2005; Calam, Jones, Sanders, Dempsey & Sadhnani, 2012; DelBello & Geller, 2001). For these reasons, it is important for medical professionals to not only help the individual with bipolar disorder but also offer care and support to the families of individuals with bipolar disorder (Hillegers et al., 2005; Birmaher, Axelson, Monk, Kalas, Goldstein, Hickey, Obreja, Ehmann, Iyengar, Shamseddeen, Kupfer & Brent, 2009).

### **Family Members Caring for Loved Ones with Bipolar Disorder**

Within the last 20-30 years, care for individuals with mental health issues has shifted from psychiatric institutions to home care by families and loved ones. This has resulted in families taking care of their loved ones with mental health issues in their homes without any formal training in most cases (Cuijpers & Stam, 2000). While caring for a family member with bipolar disorder may have positive implications, negative implications are also possible such as

burdens that caretakers may feel. Burdens such as worrying about manic and depressive episodes, feeling stress with regards to extra financial burden because of their loved ones lost wages or their own as a result of being a caretaker, and stigma they may feel as a result of their loved ones actions/mental health issues. These burdens can put a tremendous strain on the family unit (Maskill et al., 2010).

### **How to Provide Better Support for Family Members Caring for Loves Ones with Bipolar Disorder**

Family members of individuals with bipolar disorder may have many frustrating experiences when encountering medical professionals. Some of these frustrations include having loved ones misdiagnosed, released from hospital prematurely, and treating the individual's symptoms instead of the individual as a whole. In order for these relationships to improve, health-care professionals should aim to be non-judgmental, compassionate, and supportive of families of individuals with bipolar disorder (Maskill et al., 2010). In addition, caretakers of family members with bipolar disorder may improve their relations with medical professionals by seeking out information in order to provide the best care possible for their loved ones. In order to take care of themselves, caretakers may try to reduce their burden by using healthy self-care such participating in activities outside of being a caretaker (Van der Voort, Goossens & Van Der Bijl, 2007; Berk, Jorm, Kelly, Dodd & Berk, 2011).

### **Children of Parents with Bipolar Disorder**

Children of parents with bipolar disorder are more prone to develop mental health and social functioning issues as a result of genetic factors and growing up with a parent who has bipolar disorder. While it is important to focus medical attention on individuals with bipolar disorder, it is equally important to offer support to the children of individuals with bipolar

disorder with the hopes of decreasing the chances of them developing a mental health issue themselves. Early intervention is key to supporting children with parents that have bipolar disorder (Bauer, Spiessl & Helmbrecht, 2015).

### **Implications for Counsellors**

When working with family members of individuals with bipolar disorder it is important to refrain from judgment and offer compassion and support instead. Offering resources for support groups or information about how to best help their loved one would also be beneficial for family members of individuals with bipolar disorder. It would also be beneficial to research or seek out understanding as to what burdens caretakers/family members may feel as a result of their loved one's illness. Promoting positive self-care is also vital as many caregivers forget to take care of themselves (Travag & Kristoffersen, 2008; Jonsson, Skarsater, Wijk, & Danielson, 2011; Gonzalez, Perlick, Miklowitz, Kaczynski, Hernandez, Rosenheck, Culver, Ostacher & Bowden 2007).

### **Limitations and Future Research Opportunities**

Most of the research I came across was from a western perspective with a few exceptions. It would be helpful to have more research from other cultural perspectives as far as their view of mental health issues and ways in which the family can support their family member with bipolar disorder while also taking good care of themselves as caregivers. As the primary focus of this study was based on the positive and negative effects of having a family member with bipolar disorder, research was not completed on the experience of what living with bipolar disorder might be like. This research may offer families a better sense of compassion and understanding when caring for their loved ones and furthermore might increase their coping capabilities. Lastly, further research could be focussed on first hand accounts of what is it like to have a

parent with bipolar disorder as I found it very hard to find scholarly articles on this topic. This is an important area of future research as we need to understand the experiences of the children first before we can offer specialized support.

### **Conclusion**

Being a caretaker for a family member with bipolar disorder may result in feeling burdened for a number of reasons (Dore & Romans, 2001; van der Voort et al., 2009). Children may also be affected by having a parent with bipolar disorder both in social realms and by the increased chance of developing psychopathology themselves. Early intervention with children of parents with bipolar disorder may result in improved outcomes later in life (Birmaher, Axelson, Monk, Kalas, Goldstein, Hickey, Obreja, Ehmann, Iyengar, Shamseddeen, Kupfer & Brent, 2009; Ostiguy, Ellenbogen & Hodgins, 2012). In order to reduce negative effects on families of individuals with bipolar disorder counsellors/health-care workers should aim to be non-judgmental, open-minded, compassionate, and advocate for these families to get the support they need (Bauer, Spiessl & Helmbrecht, 2015).

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