#### EMPLOYMENT EXPERIENCES OF PEOPLE WITH BIPOLAR DISORDER

by

#### Sandra Hale

B.Sc.(O.T.), The University of Alberta, 1987

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#### Abstract

The mental illness called bipolar disorder creates enormous social, economic and health implications for Canadian society. Bipolar disorder (BD) causes fluctuating mood states ranging from depression to mania. Over half a million Canadians live with BD (Schaffer, 2006), and approximately 400,000 are working age, 25-64 years (Wilkins, 2004). In Canada, reported prevalence of unemployment for all persons living with a severe mental illness, including BD, is as high as 90% (Kirby, 2006). The aim of this study was to explore the perspectives of people living with bipolar disorder regarding their employment accomplishments and obstacles, and to understand the adaptive strategies they used to manage both BD and employment. Using a qualitative research framework based primarily on the interpretive descriptive approach, considered especially suited to inform health care practice, purposive sampling identified 10 people living with the extreme mood fluctuations of BD type I. Their experiences were described during one in-depth interview, a follow-up telephone interview, and findings verified through written feedback. Three main themes were revealed, related to (1) hypomania and mania, (2) stigma and disclosure, and (3) employment factors that supported or created obstacles to successful employment. Findings suggest a broader perspective of employment issues should be considered by practitioners and employers to help reduce limitations encountered by this sample of persons with BD type I. Inclusion of social, psychoeducational and organizational issues in the repertoire of job accommodations may improve employment for this population.

#### **Preface**

Chapter 2 is a qualitative study that forms the basis for a paper to be submitted for publication in a peer-reviewed journal. I presented a preliminary version of this chapter at the 2010 annual conference of the Canadian Association of Occupational Therapists, identifying my supervisory committee as co-authors. I conceived the idea for the study and designed it under the guidance of my supervisory committee (Catherine Backman, Erin Michalak and Melinda Suto). I conducted all of the employment and follow up interviews and wrote the thesis. Revisions were proposed by the supervisory committee, and assistance received for tabulating data to describe characteristics of the study sample. My supervisor reviewed data and asked clarifying questions regarding the data analysis and interpretation. It is anticipated that further critical appraisal from the supervisory committee will develop chapter 2 as a manuscript suitable for publication, with myself as primary author, and the committee as co-authors.

This study obtained ethical approval from UBC's Behavioural Research Ethics Board (BREB) certificate # H0902577 and the Vancouver Coastal Health Research Institute (VCHRI) approval certificate # V10-0027.

## **Table of Contents**

Abstrac	?t	ii
Preface		iii
Table of	f Contents	iv
List of T	Γables	vii
List of I	Figures	vii
Glossar	y	ixi
Acknow	vledgements	ix
Dedicat	ion	xi
Chapter	r 1: Introduction	1
	1.1 The history of mental illness treatment in Canada	2
	1.2 The paradigm of recovery	2
	1.2.1 Recovery exists yet the scars still remain	3
	1.3 Bipolar disorder	5
	1.3.1 Bipolar disorder type I	5
	1.4 Mental illness (MI) and employment	6
	1.4.1 Bipolar disorder and employment	7
	1.5 Employment from an occupational perspective	9
	1.6 Employment policy and accommodation	10
	1.7 Qualitative inquiry in the field of human health	12
	1.7.1 The interviews as a tool for data gathering in qualitative inquiry	12
	1.7.2 The research relationship	13

1.7.3	Situatin	g the researcher: ensuring rigour and credibility	13
1.8	Study des	ign	15
Chapter 2: T	he Qualita	ative Study: Employment eexperiences of people living with	
bipolar disord	der		17
2.1	Methods		17
2.1.1	Researc	h questions	17
2.1.2	Particip	ant recruitment	17
2.1.3	Inclusio	n and exclusion criteria	18
2.1.4	Data col	llection	18
	2.1.4.1	Screening	18
	2.1.4.2	Self-report tools to describe participant characteristics	19
	2.1.4.3	Primary and follow up interviews	19
	2.1.4.4	Email verification of preliminary findings	19
2.1.5	Data an	alysis	19
2.2	Findings		22
2.2.1	Descrip	tion of participant sample	22
2.2.2	Mania i	n bipolar disorder type I	24
	2.2.2.1	The experience of hypomania and mania	24
	2.2.2.2	The employment experiences of mania	26
	2.2.2.3	The aftermath of mania - the trails of emotional destruction	27
2.2.3	Disclosi	are and stigma	29
	2.2.3.1	Responses to disclosure at the place of employment	29
	2.2.3.2	Self- stigma you can hide it from everybody but yourself	31

	2.2.4	Employment factors	32
		2.2.4.1 Individual strategies used to assist employment	32
		2.2.4.2 The employment environment	33
		2.2.4.3 Employment choice	34
Chapte	r 3: D	Discussion	37
	3.1	Being employed and living with bipolar disorder (BD)	38
	3.2	Hypomania - the warning call to take action	38
	3.3	Mania and its aftermath	40
	3.4	Disclosure and stigma the entwined relationship in employment	42
	3.5	Factors impacting competitive employment	45
	3.6	Taking charge of employment destiny - the importance of employment	ıt
		choice	47
	3.7	Practice implications	48
	3.8	Strengths and limitations	50
	3.9	Conclusion	51
Referen	ices		53
Append	lices		71
	Appe	endix A Interview guide employment experiences	711
	Appe	endix B Follow up telephone interview	73
	Appe	endix C Letter for participant feedback	73
	Appe	endix D Candidate themes	74
	Anne	endix E Feedback received from participants	77

### **List of Tables**

Table 2.1	Sample characteristics	23
	•	
Table 2.2	Summary of main themes.	24

List of Figures	List	of	Fig	ure	S
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Figure 2.1 Data analysis	plan
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#### Glossary

**Competitive employment** refers to part time or full time employment, including self-employment, in the labour market with wages comparable to the open employment market place.

**Employment** refers to the occupation for which one is paid; it may be any form of occupation/labour, or a vocation for which a person is particularly suited or qualified.

**Job accommodations** refer to alterations to tasks, demands, or structures in a job. Examples include adjusting work hours or location, and provision of tools or equipment to enable task completion. Formal accommodations are the changes made and documented by employers, disability management, or vocational rehabilitation services. Informal accommodations are defined and incorporated by the person living with BDI to address workplace issues or job demands.

**Vocational rehabilitation** generally refers to a form of psychosocial rehabilitation where the focus is on restoring (rehabilitating) career pathways. It is used often in conjunction with other forms of psychosocial treatment and rehabilitation.

**Work** refers to something that one is doing, making, or performing, especially as an undertaking such as an obligatory duty or task, whether paid or unpaid. Paid work is synonymous with employment.

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#### **Dedication**

I dedicate this scholarly pursuit to the people who live with bipolar disorder. I have seen your struggles, I see your accomplishments and I believe in and embrace the diversity of experience you bring to the world. Keep the belief in your unconquerable souls.

I dedicate my return to university to my father Robert Stanley Hale, thanks dad for always believing in me.

#### **Chapter 1: Introduction**

This investigation explores the mental illness of bipolar disorder and employment. Bipolar disorder (BD) causes fluctuating mood states ranging from depression to mania. Over half a million Canadians live with BD (Schaffer, Cairney, Cheung, Veldhuizen, & Levitt, 2006). Approximately 400,000 people are between the ages of 25-64 (Wilkins, 2004). In Canada, the prevalence of unemployment reported for all persons living with a severe mental illness, including BD is as high as 90% (Kirby, 2006). The resulting financial implications present significant quality of life issues. Limited financial resources can impact long term health (Kirby, 2006; McIntyre et al., 2008; Michalak, Yatham, Kolesar, & Lam, 2006). Significant long term social health determinants such as housing, nutrition and community can be negatively impacted by employment challenges (Cockerham, 2007). Mental illnesses present numerous issues to engage in employment (Krupa, 2007; Michalak et al., 2006; Montejano, Goetzel, & Ozminkowski. 2005; Simon, Ludmana, Operskalskia, & Bauer 2008; Tse & Yeats, 2002). Previous qualitative research specific to bipolar disorder and employment examines the diagnostic spectrum of bipolar disorder (Michalak, Yatham, Maxwell, Hale, & Lam, 2005; Tse & Yeats, 2002). This study intends to specifically examine BD type I (BDI), a mood disorder that spans the mood extremes of depression and manic mood states. Given the scant research base specific to both bipolar disorder and employment this will add to the evolving foundation of research into the consequences of this important chronic illness.

This thesis provides an in-depth exploration of employment experiences from the perspective of people living with BDI. The factors which help or hinder employment and how these are managed elucidate important issues specific to this illness. The present chapter offers the reader a concise literature review for a comprehensive picture of this complex mental illness and employment. The history of mental illness treatment in Canada provides a backdrop to the important employment challenges people living with a mental illness confront. This includes information of the paradigm shift in mental health treatment and service delivery known as recovery. The diagnostic challenge of BDI imparts appreciation of the biomedical perspective, and the psychosocial factors impacting this illness which are increasingly recognized (Basco & Rush, 1996; Colom et al., 2003; Miklowitz, 2008; Murray, Suto, Hole,

Hale, Amari & Michalak, 2011). Both BDI and employment are defined, followed by introducing the research approach selected to guide the qualitative study.

#### 1.1 The history of mental illness treatment in Canada

Dramatic treatment and societal changes have shaped mental health care in the western world (Rae-Grant, 2001; Shorter, 1997; Sussman, 1998). The historical starting place in Canada is the 19<sup>th</sup> century. Institutions were built to provide asylum (safe housing) for people suffering from mental illness neglected in Canada's jails, poorhouses and workhouses. This protection effectively segregates them from society, shaping the social context of Canadian mental health treatment (Sussmann, 1998). Overcrowding and lack of effective treatments become institutional trademarks. Long term hospital stays for mental illness became the next treatment advancement. Out of sight and mind from the public, mental illness does not have a voice or visible presence to the Canadian public. In the 1960's and 1970's, pharmacological agents revolutionize the treatment of mental illness symptoms. Medications now offer relief from the disabling symptoms of many psychiatric conditions. A national trend to discharge patients from hospitals into community care ensues. Though this trend is well intentioned, resources for housing, employment and follow up care needed to successfully integrate people back into community roles are not considered (Morrissey & Goldman, 1984). Inadequate social housing results in homelessness and people living on the streets (Kirby, 2006). People with mental illness fend for themselves, or friends and families are left to take on care giving roles (Morrissey & Goldman, 1984). A paradigm shift begins to occur.

#### 1.2 The paradigm of recovery

Originating predominantly from upstate New York a social phenomenon known as the psychiatric survivor movement is set in motion. This movement contains the seeds of what today is the recovery movement (Chamberlin, 1990; Frese, Davis, & Walker, 1997). People discharged from hospital to community settings begin to voice their discontent with their past and present care from the mental health system (Chamberlin, 1990; Jacobson, 2001; O'Hagan, 2004). Relief from the symptoms of mental illness was inadequate to address the multiplicity of issues people living with a mental illness were left to contend with in their communities. Mental health care practice in the Western world was in a tornado of revolt

(Anthony, 1993; Deegan, 1988; Gawith & Abrams, 2006; O'Hagan, 2004; Ramon, Healy, & Renouf, 2007). The message of recovery is that living with a mental illness should not exclude someone from living well, being employed or maintaining relationships. In other words, recovery of a fulfilling life is possible. Anecdotal evidence from people living with mental illness begins a shift in long standing beliefs (Capponi, 1992; Chamberlin, 2004; Copeland, 1997; Deegan, 1988).

One of the strongest voices is Patricia Deegan who lives with schizophrenia. Her 1996 seminal talk to educators entitled "Recovery as a Journey of the Heart" is her impassioned plea for those who live with a mental illness to be seen as people first. "Those of us who have been labelled with mental illness are first and foremost human beings...our hearts are as real and as vulnerable, as valuable as yours are. We are people. We are people who have experienced great distress and who face the challenge of recovery" (Deegan, 1996, p. 9). Her words speak to the importance of moving beyond the limitations of a predominant medical model in mental health to acknowledge the psychological and social factors affecting recovery. The paradigm of recovery challenges the biomedical framework of treatment in mental health (O'Hagan, 2004). The capacity to recover function is emerging from recovery studies and altering mental health treatment practice (Frese et al., 2001). Schizophrenia was once thought to be a mental illness with a progressive deteriorating course (Kraeplin, 1913, cited in Ralph, 2000), an idea that has been debunked. The World Health Organization's (WHO) longitudinal studies demonstrate complete recovery in 20-25% of mental illness conditions (Farkas, 2007). Recovery, as the prevailing approach for mental health service delivery is sweeping the western world (Anthony, 1993; Kirby, 2006; Ramon Healy & Renouf, 2007). The recovery model broadens the scope for understanding phenomena such as employment of people living with a mental illness (Kirby, 2006; Anthony, 1993; Anthony, Cohen, & Farkas, 1999).

#### 1.2.1 Recovery exists yet the scars still remain

Despite the change the recovery movement represents, societal ramifications resulting from the separation of people with mental illness from the community in Canada endure to this day (Kirby, 2006). One of the most prevailing negative impacts of this history is

discrimination and prejudicial treatment known as stigma (Thornicroft, 2006). Erving Goffman describes stigma as a powerful negative social label, an attribute deeply discrediting, reducing that individual "from a whole and usual person to a tainted discounted one" (Goffman, 1963, p.3). When someone experiences stigma, they must renegotiate their identity with the world and themselves (Goffman, 1963; Link & Phelan, 2001). Stigmatizing beliefs focus on negative attributes which identify individuals as being fundamentally different from others. This can result in a loss of social and economic status (Link & Phelan, 2001). Stigma has been extensively studied within the social sciences literature. There is strong evidence of the negative impact of stigma to persons living with mental illness (Corrigan, Kerr, & Knudsen, 2005; Hayward & Bright, 1997; Link & Phelan, 2001). There are disturbing predicaments a person can experience once diagnosed with a mental illness. First, an individual must address the symptoms associated with the illness; second they can experience the negative beliefs and misunderstandings of the society they live in; finally this stigma can become a belief they hold of themselves or self stigma (Corrigan & Watson, 2002; Corrigan, Green, Lundin, Kubiak, & Penn, 2001; Hinshaw & Cichetti, 2000; Livingston & Boyd, 2010; Rüsch, Angermeyer, & Corrigan, 2005; Stuart, 2006). A prominent theory of stigma, by Corrigan and colleagues (2001), is based on a cognitive behavioural model. Stereotypes, prejudice and discrimination form the basis of cognition/perception of mental illness, and lead to behaviours such as social distancing from people with mental illness. The Canadian government sponsored report, "Out of the Shadows At Last," found stigma to be a significant and continuing issue for Canadians with mental illness and their families, limiting their ability to engage in housing, employment and social endeavours (Kirby, 2006). Part of the recovery process for persons living with mental illness has been to move beyond stigmatizing attitudes, particularly in employment environments (Krupa, 2009; Kirby, 2006; deVries & Wilkerson, 2003). However, the most frequent source for public information is the news media that often fails to provide accurate portrayal of mental illness (Nairn & Coverdale, 2005; Stuart, 2006). An expanding body of research specific to psychosocial issues and BD identifies stigma as a significant factor people face with this condition (Michalak, Yatham, Kolesar, & Lam, 2006; Kelly & Jorm, 2007; Lim, Nathan, O'Brien-Malone, et al., 2004; Perlick et al., 2001). A recent qualitative study finds that people with BD internalize stigma, or turn negative public perception onto their selves;

thus, stigma impacts self identity, willingness to disclose their condition and ability to move forward with life goals (Michalak et al., 2011). The significance of stigma to the present study is in recovering a role in society in an employment capacity. The unique experiences of individuals with BD in employment environments may be significant and requires further understanding. Societal beliefs, social movements and advancements in effective medical and psychosocial treatments all preface the employment issues a person with a mental illness could encounter.

#### 1.3 Bipolar disorder

Bipolar disorder, also known as 'manic depression,' is classified as a mood disorder using the Diagnostic and Statistical Manual Text Revision (DSM IV, TR, 2000). The classification of BD is defined by marked changes in mood and behaviour during periods of illness. Mood alterations range from elevated, euphoric and irritable (mania), to sad, withdrawn and hopeless (depression). The WHO currently estimates BD as the 6<sup>th</sup> leading cause of disability worldwide among adults aged to 15-44 years (Murray & Lopez, 1997). The global burden of disease is a comprehensive projection of mortality and disability from disease, injury, and other health risk factors estimated for 1990 to 2020. Updated effort to quantify the disease burden worldwide dramatically changes views about neuropsychiatric disorders according to the WHO (Mathers et al., 2002). The presentation of BD symptoms is unique and varies markedly in frequency, duration and recovery periods between episodes from one person to another. There is no known cure for BD, and there are reported high levels of suicide for BD (Mitchell, Slade, & Andrews, 2004) however there are some effective medication and psychosocial treatments which can reduce symptoms and maintain day to day function (Miklowitz, 2008; Montejano et al., 2005). A systematic review of health-related quality of life, work impairment, and healthcare costs in bipolar disorder (Dean, Gerner, & Gerner, 2004) paints a picture of significant employment dysfunction.

#### 1.3.1 Bipolar disorder type I

BD type I and type II are the two most common expressions of this illness. Bipolar disorder type I (BDI) is identified by periods of mania, major depression and or mixed mood states (shifts between mania and depression). A longitudinal follow up of 146 people living with

BDI rated the severity of their mood symptoms over a 4-year period (Judd et al., 2002). The predominant symptoms were sub-syndromal minor depressive and hypo manic symptoms. These symptoms combined were nearly three times more frequent than syndromal-level major depressive and manic symptoms, suggesting it is the less severe expression of mood symptoms that are experienced by most people living with BDI (Judd et al., 2002). BDI is differentiated from BD type II (BDII) primarily based on the mood state of mania. BDII is defined by periods of hypomania (a milder form of mania) and major depression. Type I includes the mood of mania which represents the defining characteristic for this type of BD. Bipolar disorder is largely understood from a symptom reduction, biomedical perspective. The presence of mania with a potential to progress to psychoses (a break from reality) represents a high level of severity. A severe episode of depression or mania can result in hospitalization. BDI is considered to be a long term, chronic illness with periodic relapses of depression and mania. The full impact of mood symptoms to employment function does not appear to be fully captured in the literature to date.

#### 1.4 Mental illness (MI) and employment

Participation in paid employment represents an important goal to may persons living with a mental or physical chronic illness (Backman, 2004; Waghorn & Lloyd, 2005). There are a myriad of positive benefits people with a mental illness can gain from employment (Dunn, Wewiorski, & Rogers, 2008). The Kirby report suggests that for Canadians living with a severe mental illness like BD employment represents an important economic and quality of life goal integral to their recovery from a mental illness state (Gilbert, M. in Kirby, 2006). For those people living with serious mental illness unemployment estimates are as high as 90%. American statistics for persons with a mental illness are similarly high (Dunn et al., 2008). An Australian survey reported unemployment rates as high as 75% for persons with a mental illness (Waghorn & Lloyd, 2005). In general there is a paucity of Canadian and worldwide research in mental health and employment (Kirby, 2006).

#### 1.4.1 Bipolar disorder and employment

It is widely accepted that living with a chronic, recurrent mental illness such as BD can cause a significant negative impact on employment (Goetzel, Hawkins, Ozminkowski, & Wang, 2003; Laxman, Lovibond, & Hassan, 2008; Michalak et al. 2005; Simon, Ludmana, Operskalskia, & Bauer, 2008;). The age of onset for BD is typically in late adolescence to early adulthood. Developmentally, this strikes many people in the midst of completing secondary or post secondary education, making career choices and entering the workforce (Miklowitz, 2008). The additional delay arising from an accurate diagnosis of BD taking 10-20 years (Parker, Rosen, Trauer, & Hadzi-Pavlovic, 2007) potentially further complicates the employment trajectory. The effects of the illness may limit employment while the individual attempts to understand or is uncertain of the cause of the difficulties experienced. Educational and employment goals may be delayed, affecting job prospects and creating further employment impediments (Montejano et al., 2005). The scholastic achievement of many people living with BD is higher than the general population in Canada (McIntyre et al., 2008) yet there is wide variation in the ability to continuously engage in competitive employment (Hammen, Gitlin, & Altshuler, 2000; Kusznir, Scott, Cooke, & Young, 1996). Symptom recovery from an episode of BD often occurs before functional recovery and return to competitive employment, suggesting factors other than clinical symptoms influence capacity for employment (Tohen, et al. 2000; Tse & Yeats, 2002). A Canadian study of BD type I found social support to be more predictive of employment success than symptoms of BD (Wilkins, 2004). Employment support such as advice and counseling during the job search and regarding disclosure of a mental illness is recognized as critical for mental health service users when returning to paid employment (Boyce, Seckera, Johnson, Floyd, Grovec Schneiderd, & Sladee, 2008).

The employment impact of mood symptoms is important to recognize. A longitudinal (24 month) study of work productivity found that persons with depressive symptoms are 15% less likely to be employed and have more work days missed due to depressive symptoms (Simon et al., 2008). The impact of hypomanic or manic symptoms to work productivity is more variable (Simon et al., 2008). In a comprehensive review of BD aimed at informing employers, Montejano and colleagues (2005) describe the resources most effective for

employees with BD and their family members. Recommendations include increasing awareness of bipolar disorder at the employment environment, connecting employees with BD to available treatment programs and provision of reasonable workplace accommodation. The coordination and knowledge of available programs and services should be the primary consideration (Montejano et al., 2005). Canadian treatment programs and services are offered, however, the Kirby report indicates there is a lack of collaborative communication within Canadian mental health care. There are silos or pockets of care which result in poor communication between service providers and a patchwork of services. For the person living with a mental illness it is challenging to access the services to best meet their needs (Kirby, 2006).

The economic costs associated with BD are high. It is estimated to be the most costly mental illness ranked by a US study based on medical claims cost and lost productivity (Goetzel et al., 2003). A systematic review of employed populations living with BD by Laxman, Lovibond, and Hassan (2008) found that BD imposes a significant financial burden on employers, costing more than twice as much as depression per affected employee. Most of the cost relates to lost productivity and delayed diagnostic and treatment access (Goetzel et al., 2003; Montejano et al., 2005; Laxman et al., 2008). Presenteeism (being present at work yet unproductive), presence of co-morbid conditions such as drug dependency, and stigma in the workplace are added factors compounding employment problems (Laxman et al., 2008). Though workplace initiatives are called for, specific guidelines for BD are not yet available. The most current recommended employer accommodations are noted to be relatively inexpensive, assist in decreasing the possibility of a mood related episode, and promote employment attendance (Montejano et al. 2005). These include flexible scheduling, reducing distractions in the immediate work environment, and structuring large assignments as a series of smaller tasks (Goff & Pittmann, 2002; Montejano et al., 2005). Such accommodations help decrease work-related factors that may precipitate a mood episode in BD. Clinical symptoms alone do not predict a return to competitive employment which suggests the capacity for employment is not solely tied to recovery from an illness relapse (Tohen et al., 2000; Tse & Yeats, 2002).

Qualitative research can provide some of the contextual framework often missing from quantitative study (Kearny, 2001; Thorne, 2008). Two qualitative studies specific to BD add further understanding to this complex picture. Tse and Yeats' (2002) qualitative study of 67 participants with BD used grounded theory to examine the supportive factors involved in individuals achieving their vocational goals and proposed a theoretical explanation of the wide variation of vocational success among individuals with BD. Research participants described individual supports such as co-workers, managers, and family and friends, as well as New Zealand health and social system supports. In this emergent theoretical model the term 'goodness of fit' refers to multiple personal, social, and health system factors which interact with phase of recovery and employment. The individual and his/her readiness to join the workforce, recovery from an episode of illness, job demands and workplace supports all require evaluation and a corresponding fit for people with BD (Tse & Yeats, 2002). This 'goodness of fit' suitably frames the importance of describing job strategies used to accommodate the specific vulnerabilities caused by BD. Using a sub-analysis of a quality of life study data to focus on work function, Michalak and colleagues (2005) found five prevalent themes related to the impact of BD on employment. These include lack of continuity and consistency with employment, financial and emotional loss related to work inconsistency due to symptoms of BD, illness management strategies used in the workplace, stigma and disclosure in the workplace, and interpersonal problems, predominantly related to irritability at work. In that study, elucidation of important detail related to workplace illness management strategies and employment adaptation are found specific to BDI. These two studies represent important employment factors specific to bipolar disorder which can be examined more closely with BDI.

#### 1.5 Employment from an occupational perspective

Employment represents an important domain of concern to occupational therapists and is a common goal for rehabilitation programs (Waghorn & Lloyd, 2005); it is one aspect of occupation. The term occupation from an occupational therapy/occupational science perspective represents the core domain of our profession. The defining characteristics and vocabulary has been and continues to be a source of confusion (Dunlop, 1933; Townsend & Polatajko, 2007). From an occupational therapy (OT) perspective occupation refers more

broadly to tasks of everyday life: self-care, paid and unpaid work, and leisure. Canadian scholarly discourse proposes use of taxonomy to specify the complexity of occupation (Townsend & Polatajko, 2007); realistically, this does little to address occupation as used in everyday conversation or how it differs from other common terms such as work or employment.

The profession of occupational therapy is an advent of the early 1900's. Freidland (2003) paints a picture of the pioneering days of the profession in Canada in her Muriel Driver Memorial lecture. The early days of occupational therapy are closely associated with the area of mental health. This primarily existed in mental hospitals as recognition of the therapeutic value of engagement in occupations were made. The reduced use of physical restraint was one of the noted benefits (Sedgewick, Cockburn, & Trentham, 2007). Typical of the types of OT intervention provided are vocational activities to help maintain the institution, such as laundry, cleaning, and grounds maintenance (Barager, 1934). Occupational therapists also had a role in developing employment and return-to-employment skills with clients (McDonald & Cockburn, 2005). Presently, occupational therapy services for people with BD support the development of pre-employment, employment and transition to employment usually within multidisciplinary mental health teams in many practice settings. This provides the initial steps to return to the workforce however long term follow up and employment environment issues often remain. Recognition of employment disparity for persons with mental illness is an issue federal and provincial employment policies attempt to correct.

#### 1.6 Employment policy and accommodation

Policy aimed at addressing the employment inequities includes legislation such as the American with Disabilities Act (ADA) of 1990. This American legislation was revised to include psychiatric disabilities in 1994. The equivalent in Canada is the Employment Equity Act of 1995. Monetary penalties can be levied against employers in breach of this act. In order to access these available accommodations an individual must disclose their specific condition and pursue any employer breach with a complaint process to the human rights commission.

The effectiveness of policies designed to improve the employment inequities for people with a mental illness remains largely unknown. In one of the few studies found to determine the impact of the ADA, Gioia and Brekke (2003) found that people with schizophrenia tend not to use the ADA. Forty-five percent of study participants were not aware of their rights under the ADA and even when aware of their right to a job accommodation, none of the participants accessed the opportunity. Their reasons included an unwillingness to disclose their illness for fear of a stigmatized response and a belief of reprisal. Although this study is specific to the American context and schizophrenia, it suggests governmental policy may not translate into a perceived benefit for the person with the disability. An additional purpose of employment policies is employment accommodations. As defined by the Canadian human rights code "...reasonable accommodations are required when a disability prevents the performance of an essential duty and does not impose undue hardship on the employers" (www.chrc.ccdp.ca; p. 1). Employment accommodation of physical disabilities is more visible, however, the recognition and application of accommodation to psychological and psychiatric conditions has not been widely applied (Olsheski, 2002). In 2006, the public health agency of Canada mandated employers accommodate persons with disability arising from psychological or psychiatric illness. This aims to provide people with mental illnesses equal opportunity to have their individual needs accommodated to work to the best of their ability.

Accommodations for employees with psychiatric disabilities are noted to be relatively easy to implement with minimal costs. One of the few empirical studies of workplace accommodations by , Fabian, Waterworth & Ripke (1993) reviewed retrospective data to identify reasonable employment accommodations. These were based on 231 job modifications used for 47 jobs. Reasonable employment accommodations included modifying job tasks, hours or schedules; the provision of orientation and training from coworkers and supervisors; modification of work rules and procedures, modification of job performance expectations and modification of workplace social norms.

Employers report uncertainty of the role they should take in mental health management and limited awareness of mental health conditions as impediments to effectively accommodating persons with mental illness (Montejano et al., 2005). Evidence for employers to utilize

accommodations for employees is sparse from a research vantage. Despite the policy requirements for employers, only 1% of recorded US employment accommodations are for people with psychiatric conditions (MacDonald-Wilson et al., 2002). A 2003 US federal department of occupational health report indicates that employee assistance programs (EAP) increase productivity and reduce absenteeism at a rate that more than compensates for the cost of such programs. US companies have reported savings of \$4-14 saved for every \$1 invested (Attridge, 2003); a relatively low cost for beginning to promote employment for persons living with mental illness. Understanding the lived employment experience of people with BDI adds important contextual information to expand research knowledge aimed at preventing work loss.

#### 1.7 Qualitative inquiry in the field of human health

Qualitative inquiry provides the possibility to better understand the commonality and diversity of human health conditions (Thorne, 2008). This study intends to investigate the unique human health aspects of a serious mental illness and employment with the backdrop of clinical understanding from an occupational therapist. A research approach which can align clinical knowledge with research knowledge provides valuable design logic (Thorne, 2008).

#### 1.7.1 The interviews as a tool for data gathering in qualitative inquiry

Exploration of sensitive and complex issues using in depth discussion is particularly suited to qualitative methods (Greenhalgh & Taylor, 1997). The lived experience of BD is unique and personal (Jamison, 1995). Individual face to face in-depth interviews are the key source of data for the study described in this thesis. Interviews provide a sound method for collecting data for qualitative inquiry (Mishler, 1986; Kvale, 1996; Rubin & Rubin, 2005). The interview is critical because it can describe the contextual employment challenges and successes people with BDI identify. Clinical skills, developed as a mental health practitioner over many years, aids in establishing rapport and a non-threatening approach, facilitating a purposeful conversation (Rubin & Rubin, 2005). Kvale (1996) uses metaphor to aid in understanding the research interview. He uses the Latin meaning of conversation, "a

wandering together with," to liken the interview to traveling with someone without setting an overly-prescribed route. A semi-structured interview guide is an important tool to help set the tone and direction an interview can take, therefore particular attention was paid to its development. The intent of the interview guide was to strike a balance between a wandering conversation that welcomed participant description with questions designed for the research purpose: a focus on employment experiences. The exploration of personal employment experience via a main and follow up interview will inform the research questions (DiCicco-Bloom & Crabtree, 2006).

#### 1.7.2 The research relationship

Obtaining rich informative data involves more than asking questions. Developing a research relationship with participants is considered critical to the interview (Maxwell, 2005). The initial contact made with potential research participants launches the relationship.

Developing rapport at an early stage of the research relationship assists in asking the more complex employment and illness experience questions during the interview. Recall and discussion of illness and employment experiences for people with mental illnesses has the potential to bring up difficult memories. My clinical background working in the field of mental health assists in the development of rapport and empathic responses to participant narratives to guide the in depth interview. Decisions of direct contact, face to face interviews, value for participant time and opinions all reflected the belief that the lived experience data are important. Additionally the emotional aspect of describing difficult illness and employment experiences was recognized. Acknowledging this at the start of the interview, ensuring the opportunity to stop the interview, and assessment of emotional response during the interview were employed by the researcher for all interviews.

#### 1.7.3 Situating the researcher: ensuring rigour and credibility

As an occupational therapy clinician the rehabilitative lens of my training shapes the research I have undertaken. Here, I summarize issues identified in the methodological literature that need to be considered when designing a study; (refer to Chapter 2 for procedural details of my study).

Credibility is enhanced by a commitment to reflexivity. Reflexivity aims to determine the role of researchers in generating and interpreting the data, as well as describing their experience with the research (Lincoln & Guba, 2000). For example, it is particularly important to consider my background as a mental health clinician, my past experiences with people who have mood disorders, and my own life experiences, to appreciate how living with BDI may influence and apply to this research question. To assist in this process, keeping a reflexive research journal documenting personal, educational, and cultural aspects of self is an important tool to promote the researcher's self-awareness. The creation of an audit or decision trail enhances credibility of the methods used by making them transparent. This can be likened to the process an accountant might use in maintaining fiscal information using an account ledger (Lincoln & Guba, 2000). My audit trail included my reflections about research methodology and analysis as I monitored the interview process with each participant in turn. Using the transcribed interview data and research journal entries enhanced my compassion and understanding of how dealing with this illness impacts competitive employment. I plan to utilize this learning in my future presentation and discussion of results of this research (Mays & Pope, 1995).

Peer review and member checks are an approach to verifying findings. In this project, peer review was provided by committee members and fellow graduate students. Provisional findings were sent to research participants to integrate their comments into the data analysis. Consideration of existing and emerging theories during interpretation of findings also contributes to rigor. In the present study, the theoretical framework of bipolar disorder and employment proposed by Tse and Yeats (2002) was examined for its relevance to a Canadian sample. Specifically the "goodness of fit" relating to the employment environment was carefully explored. Greater depth of understanding is found by examining formal and informal employment accommodations. Formal accommodations are defined as changes made to job structure and/or demands, documented by employers, disability management, or vocational rehabilitation services. Informal accommodations are defined by the person living with BDI to address workplace issues or job demands. Wider contextual components such as stigma and societal attitudes noted in Tse and Yeats (2002) and Michalak and colleagues' (2005; 2006) studies specific to BDI also warranted deeper exploration.

#### 1.8 Study design

The aim of this study is twofold. First, the study aims to provide a detailed examination of employment and bipolar disorder applicable to a wide audience of lay persons and researchers. The second aim is to provide some specific guidance to mental health clinicians from the perspective of people who experience bipolar disorder. The synthesis and interpretive stance of this research project is predicated on the author's clinical perspective in occupational therapy.

A guiding research approach known as interpretive description (ID) was chosen for this study (Thorne, 2008). Interpretive description (ID) is a generic research approach which provides a framework for understanding human health and the context of illness experience providing evidence to guide health decisions (Thorne, 2008; Thorne, Kirkham & MacDonald-Emes, 1997; Thorne, Kirkham & O'Flynn-Magee, 2004). As Hunt (2009) points out, ID assists in research design and orients research to the practice context of an applied discipline, which can then reflect the discipline's inherent biases and commitments. It is a method designed to broaden understanding of clinical practice not completely available through quantitative study. The ID approach requires that a variety of sources of current mental health practice be critically examined to inform the research issue. A primary goal of ID is to find themes and patterns capable of informing clinical understanding for health conditions (Thorne 2008). In this case, ID will inform occupational therapy practice with people living with BDI, with specific reference to supporting clients' employment goals.

ID is a generic methodology. It borrows methods from other qualitative traditions, pushing the boundaries of traditional qualitative methods (Morse & Chung, 2003). Tools from phenomenology, grounded theory, and ethnography, widely used in the social sciences such as sociology, philosophy and anthropology, are typically used for data gathering and analysis. Under the general approach of ID, the present study was further strengthened by principles of phenomenology used to inform the in-depth interview guide and data analysis. The central value of phenomenology is the understanding of human truths gained through human experience (Giorgi, 1997). This relates well to principle of client-centred practice espoused in occupational therapy literature (Townsend & Polatajko, 2007). Other research

methods that structure the data coding and analysis are described in detail in chapter two. The synthesis and interpretive stance is predicated from a clinical perspective in occupational therapy and aims to develop the understanding of the complexities in BDI and employment.

The study is described in detail in the next chapter.

# Chapter 2: The Qualitative Study: Employment experiences of people living with bipolar disorder

This qualitative inquiry provides in-depth understanding of the employment experiences of people living with bipolar disorder type I (BDI), to better understand how people manage their illness and competitive employment. Experiences are examined from the perspective of the person living with the illness.

#### 2.1 Methods

#### 2.1.1 Research questions

The specific research questions are:

- What are the competitive/paid employment experiences of people with BDI?
- Are there formal and informal employment accommodations (changes made by the individual or employer) identified and accessed by people with BDI? What is the result of these changes to the employment experience?
- What adaptive strategies have people with BDI used in addressing their specific vulnerabilities in meeting job demands and work conditions? What have been the results of using these strategies?

#### 2.1.2 Participant recruitment

Purposive sampling was used to recruit men and women with BDI and recent employment experience. Recruitment began following approval from the University of British Columbia (UBC) behavioural research ethics board. Study notices outlining the purpose, eligibility, and anticipated time commitment were circulated and posted to share with the members of the following agencies: six regional (Lower Mainland of British Columbia) branches of the Canadian Mental Health Association (CMHA), the Mood Disorders Association (MDA), and the UBC Mood Disorder Clinic. Advertisements were also made available to attendees of a BD community consultation and research day who expressed an interest in participating in

research related to employment. Interested potential participants contacted the student investigator (SH) by phone for an initial screening. Upon receipt of signed consent forms data gathering began.

#### 2.1.3 Inclusion and exclusion criteria

Adults between the ages of 19-55, with a diagnosis of BDI confirmed using the Mini-International Neuropsychiatric Interview (MINI), competitively employed in part-time, full-time or contract work of at least 3 months duration within the last two years were considered eligible. The two-year time frame was chosen to maximize accurate recall of employment experiences. Participants also needed to be capable of giving written, informed consent and communicate fluently in English, as all screening tools and data collection were in English. Potential participants who had severe depression or mania, determined by the standard clinical criteria of the MINI, Beck Depression Inventory-II (BDI-II) and the Young Mania Rating Scale (YMRS) were excluded or their involvement postponed until symptom resolution.

#### 2.1.4 Data collection

There were five contacts with participants: a telephone conversation to screen for eligibility and arrangement to send self-report questionnaires; a confirmatory diagnostic interview conducted by a qualified research assistant; an in-person, in-depth employment experiences interview; a follow-up telephone interview; and an email invitation to invite comments on preliminary findings.

#### 2.1.4.1 Screening

Following an expression of interest in the study, initial telephone contact to explain the study and answer questions was made by the student researcher (SH) to potential participants. Confirmatory diagnosis of BDI was made by a research assistant qualified to administer the Mini-International Neuropsychiatric Interview (MINI, version 5; Sheehan et al., 1998) and the Young Mania Rating Scale (YMRS; Young, Biggs, Zeigler & Meyer, 1978).

#### 2.1.4.2 Self-report tools to describe participant characteristics

Demographic information, presence of depressive symptoms, quality of life, and employment function were gathered using self-report scales mailed to participants. The Beck Depression Inventory-II (BDI-II; Beck, Steer, & Brown, 1996) is a 21-item scale that is widely used in mental health studies to indicate minimal, mild, moderate or severe depression, based on the past week. Scores in the range of 0-13 indicate minimal depression, 14-19 mild depression, 20-28 moderate depression, and 29-63 severe depression.

The Quality of Life in Bipolar Disorder (QoL.BD) questionnaire rates overall quality of life based on a range of work and leisure experiences, behaviours and feelings within the past week (Michalak & Murray, 2010). The Lam Employment Absence and Productivity Scale (LEAPS; Lam et al., 2010) measures current absence and productivity at work within the last two weeks. It was completed only by currently employed participants. A score of 0-5 indicates minimal work impairment, 6-10 mild work impairment, 11-16 moderate work impairment, 17-22 severe work impairment, and 23-28 very severe work impairment.

#### 2.1.4.3 Primary and follow up interviews

The in-depth employment interviews, lasting 90-120 minutes, were designed to be conversational, yet incorporate key questions from an interview guide designed specifically for this study (Appendix A). A 25-30 minute follow-up telephone interview (Appendix B) to clarify and expand upon issues discussed in the initial interview was used to enhance the credibility of the data gathered.

#### 2.1.4.4 Email verification of preliminary findings

Once preliminary findings were documented, a short summary was sent to participants by email to invite their comments. These were used to verify main themes.

#### 2.1.5 Data analysis

The primary function of qualitative data analysis is to bring order and meaning to massive amounts of data (Bloomberg & Volpe, 2008). Qualitative data is rich in description and

finding the common threads tying the entire data set together required frequent and flexible data review. The interpretive descriptive (ID) approach borrows from established social scientific research to provide analytic structure. The use of constant comparative methods (Charmaz, 2006; Guba & Lincoln, 1994) assisted in identification of common and divergent views from the interview data. Thematic analysis offered a flexible approach for identification and development of important concepts, and provided a rich, detailed account of the data (Braun & Clarke, 2006). Phenomenology provided the foundation for examining the interview data to understand the meaning of lived illness and employment experience (Giorgi, 1970).

The steps used in analysis are outlined in Figure 2.1.

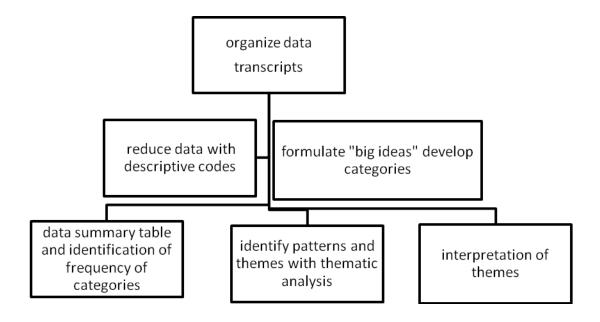


Figure 2.1 Data analysis plan

The data analysis process unfolded as follows.

**Step 1: Organize data.** Within 48 hours of each primary and follow-up interview the audiotapes and written notes made during the employment interview were reviewed. Transcriptions of each completed interview were typed within a 2-3 week timeframe by an

experienced transcriptionist. Each transcription was reviewed by the student researcher (SH) to ensure accuracy with the recorded interview.

**Step 2: Reduce data with descriptive codes.** A word or short phrase described the basic topics identified in each transcript. Broad, descriptive codes formed the first cycle of coding. This type of coding is considered appropriate for virtually all qualitative studies (Miles & Huberman, 1994; Saldana, 2009).

**Step 3. Formulate big ideas and develop categories.** The descriptive codes were then examined for similarities. Recurrent elements found across interviews were compiled representing the common threads of the employment and BDI experience and represented the "big ideas" (Bloomberg & Volpe, 2008). Categories were created by grouping similar big ideas together. Interview transcripts were reread to deepen understanding of the developing themes. Each time a category was created to verify that the category adequately reflected substantive or important portions of the text.

Step 4. Form data summary tables and identify frequency of categories. Given the complexity and uniqueness of employment experiences, data tables were created to reach more clarity in conclusions. Data summary tables noted the frequency of certain categories, though prevalence alone did not dictate development of a theme. A number of considerations including researcher judgment and determining if a category captures an important element relative to the research question were primary considerations for creating a theme (Braun & Clarke, 2006). Large visual displays illustrated the formation of provisional categories. These initial provisional categories were made recognizing a cautionary note from Miles and Huberman (1994) that "these are hunches and they may or may not pan out as a major theme" of analysis (p. 72).

Step 5. Identification of patterns and creation of themes using thematic analysis. The data summary tables and visual displays of recurrent concepts were collapsed into a smaller number of constructs to form patterns (Miles & Huberman, 1994). Using an inductive (derived from the data) approach the developed patterns were reviewed against the interview transcript passages to determine the collective importance that participants gave to certain

concepts. For example, examination of the theme of mania was reviewed across the entire data set. The importance of this potential theme was made by examining discussions related to the personal and employment impact of mania experiences. This particular concept was collated, compared to the transcription extracts, and clinical knowledge of this mood state applied to produce a group of candidate themes (Braun & Clarke, 2006). This set of candidate themes formed the base for the next phase of analysis, interpretation of themes.

**Step 6. Interpretation of themes.** A set of candidate themes or initial findings was sent to all participants for their input (Appendix C). The responses received from participants (Appendix D) were integrated into the findings. This process assisted in choosing, defining, and naming final themes, settling on three larger themes, each with two to three contributing subthemes. Final themes were refined further by choosing specific text extracts used to illustrate a theme. These themes and the researcher's interpretations constitute the findings. The quotations used in the findings provide the rich details that encompass the varied and unique illness and employment experiences from the perspective of study participants.

#### 2.2 Findings

#### 2.2.1 Description of participant sample

Purposive sampling successfully identified 10 individuals with BDI, 6 women and 4 men. This specific sample represents a predominantly middle-aged group, diagnosed with BDI type I, with numerous competitive employment experiences to draw from. Current job titles included lab technician, manager, counselor, and administrative assistant. Part-time, full-time, contract and self-employment positions were all represented. This does not exclusively demarcate the employment experiences informing the analysis because past employment was also discussed during the in-depth interviews. Nine participants completed the self-report instruments on clinical and employment characteristics detailed in Table 2.1.

Mean scores for the LEAPS scale, a measure of work impairment and productivity, were 6.1 (range 0 through 28), indicating mild work impairment. One caveat to consider here, however, is that although the LEAPS was the best available scale, it has not been validated for BD samples. The participant group showed mean scores of 12.4 on the BDI-II, indicating

mild depression. For the YMRS, mean scores were 3.4, indicating hypomanic symptoms in the mild range. Finally, QoL.BD scores also demonstrated little impairment (mean scores were 170.9, SD 3.7). The purpose of using the quantitative measures was to provide descriptors appropriate to a mixed clinical audience for the purpose of comparison to the clientele with whom they may work. Additionally, these descriptors provide an indication of the current status of the sample in relation to their current state of recovery. Although the quantitative measures suggest minimal symptoms, the qualitative data provide numerous issues for consideration.

The competitive employment experiences of the study participants demonstrated a diverse range of employment endeavors. Their unique experiences of the challenges, accomplishments, and maintenance of competitive employment while managing bipolar disorder type I (BDI) are described. The findings are presented in three main themes, each containing two to three sub themes, as outlined in Table 2.2. Pseudonyms are used to protect confidentiality of participants.

**Table 2.1. Sample Characteristics.** 

Variable	Number reporting	Frequency	Percent
Sex (females)	10	6	60
Currently employed (yes)	10	9	83
		Mean	Std Dev
Age	8	43.0	9.0
Beck Depression Inventory-II (BDI-II)	8	12.4	8.4
Lam Employment Absence and Productivity Scale (LEAPS)	8	6.1	3.7
Young Mania Rating Scale (YMRS)	9	3.3	4.2
Quality of Life in Bipolar Disorder (QoLBD)	8	170.9	38.1

Note: Std Dev = standard deviation

Table 2.2 Summary of main themes.

Main Themes	Sub-themes
Mania in Bipolar Disorder Type I	the experience of hypomania and mania
1 y p c 1	• the employment experiences of mania
	<ul> <li>the aftermath of mania – trails of emotional destruction</li> </ul>
Disclosure and Stigma	responses to disclosure at the place of employment
	<ul> <li>self-stigma, you can hide it from everyone but yourself</li> </ul>
Employment Factors	individual strategies used to assist employment
	• the employment environment
	• choice of employment

#### 2.2.2 Mania in bipolar disorder type I

#### 2.2.2.1 The experience of hypomania and mania

The majority of participants described depression as the initial diagnosis received from a health care practitioner. The typical medication treatment for depression, prescription of antidepressants, followed. A diagnosis of BDI was made only after individuals experienced a manic episode. For some participants, a clear diagnosis of BD sometimes took years. Most participants found the diagnosis and treatment with medications to be a long, arduous path fraught with difficulties as reflected in Pete's description: "Every time I went back to the doctor, I was put on a higher dose of an antidepressant...then I went psychotic and I disappeared for a few days. I was up all night, not sleeping."

For most participants the initial stage of their illness represented a high level of confusion. This confusion was heightened by the illness state and the lack of clear information as described by this participant's first experience following a manic episode.

...the problem was I didn't know anything about it (bipolar disorder) at all, I didn't know anybody that had it and I didn't have any information. The psychiatrist didn't actually give me any information. I didn't get a booklet, or a piece of paper or anything. (Deb)

Depictions of the course of the illness from hypomania to mania varied. The symptoms common to hypomania included increased energy, heightened mood and increased energy. These behaviours were not always initially seen as symptoms and were frequently viewed as personality traits or characteristics rather than symptoms. Hypomania represented a state of illness with considerable variability. Each participant had unique features of hypomania. Some people experienced long periods of hypomania before mania occurred, while others had short intervals of hypo manic symptoms. The symptoms of hypomania could last for weeks and months or they could shift to manic symptoms in a matter of hours or days. The impact of hypomania on employment also varied considerably. The behaviors often seen with the hypomanic mood state can be deemed as desirable, particularly in an employment context. Bill found his hypomania traits beneficial to employers in his employment environment. "They [the employer] worked with me and used my "bing" my "pizzazzy" self to promote everything that they were doing."

Hypomania was described as the precursor to mania, representing a time to take action. The signs of hypomania often went unrecognized by the participant and health care professionals early in the diagnosis. With time and experience, unique illness symptoms were recognizable for each participant. Some participants self-managed their medication by increasing or decreasing the medication doses to contain symptoms. Other participants obtained advice from their health care practitioner and/or made lifestyle changes to maintain employment stability. The critical self-management employment skill identified was recognition and prevention of hypomania before it progressed, as described here:

I have to contain the hypomania. If we're talking about the point where it goes to mania then I've lost the battle. I'm not going to be going into work, for sure not. I think the intervention stage needs to be sooner than that... if I'm concerned, I have extra medication or just try to take it easy. It's pretty effective, the medication that I have and I just gotta get a good two nights sleep and I'm back on track. (Lucy)

The description of hypomania was difficult for participants to describe. This could be due to attempting to recall details from a time of impending illness, or the challenge of naming specific changes to a chronic and changing condition. Untreated hypomania generally resulted in the eventual mood state of mania.

#### 2.2.2.2 The employment experiences of mania

The majority (9/10) of participants described having a manic episode while working, many while at their place of employment. The employment repercussions contrasted considerably. Manic episodes experienced at the employment site frequently led to unresolved employment consequences. One employer provided supportive medical, psychosocial, and formal employment accommodation assistance. When mania was the predominant expression of this illness employment tasks were significantly affected. However, attempts made to continue employment were not seen as a possibility for most participants. Frequently participants required hospital stays to stabilize their mood; for some this was a week or less and for others longer stays were described.

When you're manic, you have no sense of appropriateness. ... I could do something, say something inappropriate, something that's supposed to be confidential where I've lost all ability to keep my mouth shut...I could really embarrass myself and be a liability...because I just have no discretion at all and that's worrisome. (Ramona)

Responses from supervisors and co-workers were diverse. There were varying degrees of misunderstanding of manic behavior and a general lack of knowledge of BD. The individual with BDI was often uncertain about how to best respond to misunderstandings. Some participants wanted employers to play a more active educational role, using written information or employment in-service time to explain mental illness. By virtue of an absence for a hospital stay or a break from work, the employee with BDI believed co-workers knew they were unwell. This was not generally openly addressed by the employer or the employee with BDI. Most participants perceived a negative response from others to their manic state if it was acknowledged while employed. The misunderstandings manifested in various fashions. One form of misunderstanding was a belief that bipolar disorder was not an illness requiring treatment. Other participants perceived misunderstandings from the avoidance or

silence experienced from co-workers and supervisors in their employment environment. In this case the participant heard the disbelief directly from a co-worker.

I had a couple people ... they didn't believe that this stuff [BD] existed. It wasn't an illness; 'you just can't take the pressure.' So when I came back [to work from the hospital] I was embarrassed, my confidence was just shot...just shattered. (Pete)

Though perception of events can be colored by the history of their illness experience, participants recognized the deleterious impact manic behavior could have on employment situations; however, they also explained that once mania started it was not always possible for them to control or manage it on their own. Understanding, caring, compassionate assistance to obtain treatment was needed at this point. One participant described compassion found in her long term employment environment from co-workers and an employee health plan. This employer had an organizational structure designed for immediate, comprehensive employer response to her manic episode. This quick, efficient response was unusual. Most participant descriptions reflected a lack of effective response from employers. A variety of employment consequences to mania were described. These consequences included loss of employment without proper notice, job elimination while in hospital, and employer avoidance of the employee with BDI, as depicted by Ed: "I was never told that I was fired ... basically I got a call saying 'please don't come into the store anymore." They never said you're fired, they just said please don't come into the store anymore."

This type of employment response left a lasting impression upon participants. Typically this was reflected in not discussing their illness experience within employment contexts.

Attempts made to address employment issues were often met with vague directives from their employer to "rest" or "take care," however, this did little to assist the person with the illness to return to employment. The lack of knowledge about BD and how to respond to mania essentially reduced the possibility of obtaining support and understanding from within these work environments.

#### 2.2.2.3 The aftermath of mania - the trails of emotional destruction

Following a manic episode many participants attempted to make sense of the behaviour or communication which had occurred while they were manic. Often these recollections were patchy, leading to confusion and concern over who they had spoken to, what was said or done, and the repercussions. Participants described the emotional fallout after mania as a major contributor to the depression that typically followed. Guilt, remorse, and shame were all used to label the emotional responses following mania. The communication and behavior of some participants when manic seemed so uncharacteristic and inexplicable to themselves, it was seen as too difficult to explain to others. Some participants perceived their behaviors as damaging certain people and relationships in ways too severe to repair. The episodes also battered feelings of self-worth and confidence, fuelling the emotion of depression:

You just destroy all your relationships; destroy your reputation, the people you work with, and all the people you go to school with. I did a pretty thorough job of making contact with everybody I knew...the depression had everything to do with the aftermath of the mania, but I think that in retrospect, the mania was incredibly disruptive. And that was the period of time that I just did a lot of things that I intensely regretted. (Bob)

This particular quotation was understood by other participants as a common experience following an episode of mania. "I was in a huge depression. I just went right off the edge because of all the guilt. There's such a feeling of guilt and remorse over the manic episodes, that it really catapults depression." (Pete)

Participants further identified the lack of available psychological support to address the manic episode as particularly daunting. While trying to address the emotional impact of mania from an episode of BDI, the inaccessibility of professional support, aftercare, and access to information also contributed to depression. As described by one participant, a focus on medication management with condensed appointment times was inadequate to address other issues:

I think the closest thing I've seen to immediate care is what they're doing at the MDA (Mood Disorders Association). But it's not perfect. At times I feel like it's dial-a-date, that five minute date thing... you get your few minutes in there and then, you know, discuss meds and then they move onto the next person. It's overloaded with people. I only found out about the MDA because of that other research project. (Pete)

The mood characteristics of BDI can be varied. Participants described symptoms of hypomania, mania, anxiety, and depression. Surprisingly, depressive symptoms were less

disruptive to employment than was mania. Periods of deep depression and persistent low levels of depression were also depicted as part of life with BDI. Depression can commonly follow an episode of mania. Some participants described a deep depression following a manic episode. In terms of career disruption, however, mania led to more immediate, stigmatizing events. During the employment interviews these periods of mania and their impact were described in great detail. Low levels of depression were portrayed by some participants as manageable with regard to their employment. Though depression was present they continued with their employment responsibilities as illustrated by these two participants. Deb relayed, "...see for me, it's like mania and a bit of depression, so I mean I'm back to where I'm not feeling great emotionally but I mean you can still work..." and Pete stated, "I find that for the most part, though I'm stable, I am always in a low-level state of depression. I am right now, in that sort of low-level depression." (Pete)

Interviews also revealed that although the majority of participants understood and had experienced stigma, this was a less significant focus of employment discussions. Disclosure of the illness and concern over the possibility of a relapse of BDI was of greater concern.

# 2.2.3 Disclosure and stigma

#### 2.2.3.1 Responses to disclosure at the place of employment

Disclosure for some participants was an unpleasant, negative experience. These highly stigmatizing experiences, some leading to loss of employment without proper explanation, often resulted in non-disclosure in future employment situations. Consider this statement from Claire: "I told my immediate supervisor that I had bipolar disorder, a mood disorder and it was within that week that I was fired and I don't think that was a coincidence."

Such experiences can be demoralizing, and work against advice to share medical information and seek support. It is only logical that Claire would be reluctant to disclose her diagnosis in future employment settings, and stories like this may perpetuate stigma and reluctance among others with BDI. Another participant described an unwillingness to disclose his illness to future employers based on a previous employer's handling of his BDI disclosure. In an attempt to be forthright Ed disclosed his diagnosis to a human resources staff member. He described the human resources approach to this disclosure as a complete bungling of the

issue to his supervisors. "I tried this (disclosure) thing and it failed so badly. There's no point in disclosing ever again ... regardless of how much policy you put in place or whatever, there's still stigma. In employment you raise no red flags."

Following disclosure, avoidance of the issue of BD was another common response. Discussion of the illness impact and its treatment were simply not addressed in the place of employment by management or supervisors. Bob said, "I never felt overt stigma, not at work...yet I think the ability to do my job was compromised but there wasn't any real assistance or active accommodation. No one was open and really spoke about it." Participants described this avoidance as a missed opportunity by employers to better understand their illness and to address the performance issues that may have been effectively accommodated.

The issue of disclosure to co-workers was thought by most participants to be optional and judiciously managed. Some participants felt comfortable in discussions with co-workers; others did not see any benefit or need to disclose to co-workers or supervisors. A noted difference related to disclosure and stigma came in the comparison of those participants with a longer history of living with BDI. Those with earlier negative, stigmatizing reactions seemed to view the current situation as more tolerable but still requiring improvement.

Not all disclosure responses were negative. Employer responses to disclosure of BD were experienced by two participants as surprisingly positive. Interestingly, these two participants waited long periods of time prior to disclose to their manager or supervisor. Familiarity with the illness was expressed by the employer, having known a friend or family member who also had BD, or a calm understanding response provided relief for the person with BDI. "It took 7 years to disclose and apparently there is a lot of depression in his [employer's] family... it was just nice to share it with him; he was really great about it." (Deb)

The majority of participants did not disclose without consideration of the possible consequences of doing so. Considering participants as a collective, judicious disclosure perhaps best described their stance. Participants thought about disclosure to employers as a hindrance for most employment situations. The anticipation of a negative reaction or a hyper vigilance of their actions which could be inaccurately attributed to BDI was described by

some participants; a common sentiment was "I want to be seen as the person first not the illness."

### 2.2.3.2 Self- stigma you can hide it from everybody but yourself

The ricochet effect of negative attitudes directed at oneself, known as self-stigma, affected some participants more than others. For some participants stigma experiences had happened years ago and were not currently an issue. Yet, self-stigma remains a factor in attaining employment, despite options that might otherwise have been taken. "Well, who would want me?" stated one participant. Another participant was constrained by the loss of benefits and the impression that the employment opportunity at a sister company would be hampered. "People talk..." he said, referring to inherent knowledge communicated between staff. The impact of self-stigma is described by another participant in this way:

"...the degree of self-criticism and self-stigmatizing itself is the filtering that I do. I limit what I expose to others and how I present myself to others ...'cause I don't feel that I experienced a lot of stigma, but in retrospect I think that's because I really beat myself up before I gave other people a chance to ... establish some really unproductive patterns of thinking." (Bob)

Negative reactions and attitudes towards mental illness represented an experience the majority of participants shared. Many participants said that although they could not change another person's perception of BDI, the residual negative impact was long-lasting. One participant had experienced numerous losses related to employment, socioeconomic status, and career choice. The cumulative impact of BDI from repeated employment disruption due to hospitalizations, housing loss, and financial stress all impacted a sense of self-confidence, promoting feelings of hopelessness. The identified aspects that assisted with rebuilding confidence began with volunteer work, followed by other types of paid employment. This participant stated employment (volunteer or paid) contributed to her confidence and self-identity.

Another participant portrayed stigma as a perception arising from within a person.

Interestingly, although it may be related to other factors, this is the participant who described a very responsive accommodating employment environment.

"No, I've never felt stigma. And my interpretation on stigma, not to negate it on anyone else, but I've kinda been of the opinion that stigma is something that you allow yourself to feel based on other people, so I've never experienced that." (Carol)

The development of self-stigma followed very different trajectories. Some participants were more impacted by the severity of symptoms of BDI and the resulting influence they could have. Overall, most participants expressed a reluctance to disclose BDI within employment settings.

### 2.2.4 Employment Factors

The interview questions related to strategies used for employment revealed a vast array of factors that could positively or negatively impact employment. Participants frequently described individual strategies they developed to deal with specific employment tasks; broader factors such as the employment environment and choice of employment were also considered.

#### 2.2.4.1 Individual strategies used to assist employment

The vast majority of participants used informal strategies to concurrently manage employment demands and living with BDI. These included a multiplicity of techniques to take charge of their employment tasks and environment to augment their employment performance. Some examples of straightforward workplace modifications described by participants included the use of clear, written performance expectations, and minimizing interruptions during certain time periods (such as having phone calls directed to another number and retrieved at a later time, turning off auditory cellular phone and email alerts or put on silent while performing particular tasks). The use of technology such as auditory or written reminders, calendars, day-minders, and written lists assisted with scheduling functions. Planning, preparing and prioritizing employment tasks in writing at the beginning of each day were strategies also used to assist in organization.

Participants stated the importance of managing their own health as one of the best methods of managing employment. This required individuals to recognize and understand their unique signs and symptoms of BDI, and have knowledge of the treatment interventions of most

benefit to their ongoing health. This quote represents one strategy for avoiding an illness relapse of mania.

I know what my triggers are. I know... when I wake up at three in the morning and I'm thinking about all the solutions for the world's problems and it's like okay ... if I don't fall back asleep in five or ten minutes that's when I jump on it... I don't let it get out of hand. (Lucy)

Individual strategies were frequently described in response to questions asking about employment accommodation. The one participant who did have formal employment accommodation identified part-time work and being exempt from shift work as the factors that assisted most in maintaining her continued employment.

## 2.2.4.2 The employment environment

The employment environment was defined by participants as the organizational structure, the physical setting, and the social environment. Each of these components was an important factor in sustaining employment. Organizational structures which may adhere to rigid time frames and models of work were viewed as deterrents to reliably performing employment tasks for some participants.

Virtually all participants described a flexible schedule and task performance arrangement as the best approach for successful employment. For example, Maria explains how she sought out a flexible job:

...the reason I got into that line of work was it was flexible, it was something I could do sort of on my own terms and on my own hours. I could work as much or as little as I wanted and the hours that I wanted to do it.

Flexibility to work from home was another example made possible by utilization of available communication and technological devices that many employers have. Deb notes:

...we now have remote access to our servers at work, so we can do our work at home... we had a really pressured week the other week, and I knew that if I went in and I was in that [employment] environment where everyone was like (moaning), then I'd just lose it. So I just stayed at home, I actually stayed in bed with my laptop, and worked all day from there, because I knew that it could keep my body calm.

One participant valued a workplace schedule commonly known as a flex day. A paid day off is accrued every two weeks by working longer each working day to add up to one work day. Despite the slightly longer work day Lucy described the positive impact of an additional regular day off in terms of managing BDI.

The type of environment most conducive to effectively managing BDI was described with regard to the stressors located within it. This typically referred to interpersonal factors with co-workers, as one participant stated "...you can just feel it when you walk in" referring to the emotional vibe one can get from the people employed there. Certain employment characteristics illustrated effective management with BDI. Characteristics that accommodated participants' social and emotional needs were most frequently mentioned. A social environment with tension and conflict, "whether it's highly competitive or just conflict within staff that...isn't being resolved, or an unhealthy work environment emotionally" was described by Lucy as highly undesirable. In addition to environmental factors, study participants discussed important choices they made that related to the actual type of employment. Particular types of employment and the characteristics considered that could impact their symptoms of BDI are described next in employment choice.

### 2.2.4.3 Employment choice

Participants recounted the employment choices they found conducive and ones to avoid in living with BDI. This particular participant sample had a wide range of employment experiences to draw from in making these comments. The typical age of diagnosis of BD, generally in young adulthood, was common but collectively participant experience in employment was as diverse as illness experience. Two participants were not diagnosed until their latter career lives. This factored into decisions related to career choice for one person while less so for the other. Random, irregular types of employment tasks or organizational practices were seen as undesirable for people living with BDI. Bob noted that unpredictable employment expectations were problematic; he described these as "...high workplace demands that are inconsistent and at times unknown, and that are always kind of moving around and switching."

Likewise, jobs that adversely impacted sleep were considered an ill-fit for long term employment.

...I think expectation of hours, like, we've got a deadline, gotta work all night, if it's necessary- I don't think I could do that job. Or shift work...Any kind of job that expects me to work with changing my sleep pattern, I'd be very leery of. I think for me that'd be a real mania trigger. (Lucy)

Self-employment and contract work were chosen by roughly half of participants for the scheduling flexibility and the autonomy they offer. Self-employment was combined with maximum allowable monetary benefit available through the Canadian disability system. Augmenting employment with this system had pros and cons. This available social safety net provides financial support for persons with serious mental illness, however, the process of acceptance and the rules surrounding the aid do not always match the episodic nature of an illness like BDI. The Canadian Mental Health Association (CMHA), a national not-for-profit organization, identified a number of issues in a position paper outlining a number of recommended changes for persons with severe mental illness. Individuals can become caught in a "jurisdictional tangle between Federal and Provincial government involvement in the funding and management of these various programs" (CMHA, 2001, p.2). This financial support was described by study participants as onerous and difficult to understand. The significant associated challenges of applying for disability and the requirements of this system were mitigated by the security of income, the health and dental benefits provided. Participants who opted for this supplementary financial aid along with self-employment demonstrated considerable tenacity. Reconciling the emotional aspect of "going on disability" was difficult in varying degrees for the participants using this system. Emotional responses such as feeling demoralized and humiliated by the excessive bureaucracy involved added to the impact of BDI. Consequently, participants strove to balance "going on disability" with employment choices that accommodated characteristics of their illness in order to be self-sufficient, as demonstrated by these next examples:

... my mood has just been so much more stable since I have been working on my own; I have more choice about my hours and my day to day work schedule. ... it was really hard (to go on disability) but I think about it like recovery cash. (Claire)

The thing that's been good about disability is just the security of the income, the steadiness of it that I can count on it no matter if I get ill or not. (Maria)

Employment choices made by study participants were considered in the context of BDI when possible. Some participants received their diagnosis later in their employment careers; this could limit employment options primarily due to the economic disadvantage of switching employment and losing benefit plans covering health related costs. This chapter aptly concludes with findings about participants' employment choices, as a transition to the concluding chapter, which begins with reflections of the researcher's choices that led to this thesis.

#### **Chapter 3: Discussion**

In the genesis of research, the topic chooses you as much as you choose it. My choice of examining BDI and employment comes from a culmination of clinical, personal and life experience. My employment as an occupational therapist has spanned a 23 year period. A clinical shift in 1992 to working with people living with mood disorders in the acute phase of their illness set in motion a journey toward this thesis. One day, when talking to someone in their hospital pajamas after a serious episode of mania, I asked what he would like to do when he was better. He responded, "I want to work. Not a volunteer job - I want a real job, to earn money, pay my rent... I want to work." That conversation stayed with me for years and represents the frontline clinical motivation for this thesis. My employment as a clinical practice leader has exposed me to the numerous issues facing clients and families using the mental health system.

My personal health experience, living with multiple sclerosis, frames the experience of living with a chronic, episodic, yet at times, easily concealed illness much like BD. My compassion and understanding for people living with a variety of chronic health conditions amplified following my diagnosis 11 years ago. I was dedicated to working with people living with a mental illness, who struggled with often misunderstood conditions. I wanted to contribute to a better understanding mental health conditions, particularly mood disorders.

A pivotal connection came from meeting and working with Dr. Michalak. Her visionary research agenda for people living with BD piqued my interest in conducting my own research. I observed people who had severe episodes of illness, while I had worked with as an occupational therapist in the acute care hospital system, both struggle with relapses of their illness and progress forward. The possibility of attaining competitive paid employment became evident for some. Ultimately, there remained many questions related to employment struggles for people with this illness. Are these struggles solely the result of individual factors or are there added issues impacting employment goals? How can professionals and services best function in partnership with people living with this condition to improve their employment options? These questions solidified my decision to conduct research and framed my research questions for this novel exploration of the condition of BDI and employment.

The aims of this concluding chapter are to integrate the findings from the qualitative study with the current knowledge in the area of BD, to discuss the employment challenges and accomplishments in the context of BDI and finally, to discuss the practice implications of this for health care professionals.

### 3.1 Being employed and living with bipolar disorder (BD)

BD is a complex illness with a wide spectrum of illness and recovery states. Competitive employment is a common goal for persons who experience mental illness (deVries & Wilkerson, 2003; Michalak et al., 2005; Tse & Yeats, 2002). Living with BD can complicate an individual's capacity to successfully engage in this important life role. Canadian unemployment and underemployment statistics indicate some people with BDI experience lack of employment (Wilkins, 2004), however, the results of the present study indicate it is not a definitive outcome. The issues in seeking and maintaining employment and the adaptive strategies to address employment vulnerabilities with this illness were fully examined with a sample of people who had recent competitive employment experiences. Though the participants identified unemployment and underemployment experiences these were discussed in the context of employment over the course of many years. This provides an interesting view of the illness along with changes in the world of employment from the vantage of people with lived experience.

#### 3.2 Hypomania - the warning call to take action

Hypomania is both a symptom of bipolar disorder and a forewarning for intervention. The course of the illness symptoms described by participants from hypomania to mania conveys a reasonably common trend in occurrences of mania. While the intensity and interval of symptoms varied, the final result was mania for all participants in this sample. For a majority of study participants, understanding and addressing their unique signs of impending hypomania was critical to avoid a full-blown episode of mania. This unique personal health knowledge often took participants years of difficult, autonomous learning. During the employment interviews most participants had some difficulty describing their hypomania symptoms. Indeed, the subtle signs of hypomania are frequently missed by physicians and health care providers (Angst et al., 2003; Cassano et al., 1998; Dunner et al., 2003). Yet it is noticing the subtle signs of impending illness that some participants found prevented full-

blown mania. This is supported by other research related to psycho-education with BD patients. A preventative tool for staying well is the provision of education for early identification of the hypomania prodrome (Lam & Wong, 1997; 2005; Mansell & Pedley, 2008). A 1999 study by Perry and colleagues found important clinical improvements came from identifying mania. Education to assist individuals with BD in early recognition of hypomania symptoms and seeking early treatment are cited in significant clinical improvements for the reduction of manic relapse episodes. Increasingly, the importance of teaching skills for self-management specific to BD is recognized (Murray et al., 2010; Russell, 2008). Self-management strategies related to maintaining employment stability were reflected by some participants in the present study and impart a viable strategy in support of employment goals. Rapid shifts from hypomania to mania, which can occur in hours or day to day for some individuals, were difficult to detect or arrest. In employment situations accessible immediate attention usually is needed for the employee with BDI. Accurate recognition of hypomania symptoms has been noted to be difficult for health care providers (Thomas, 2004) and complete self-reliance in identifying these symptoms can be difficult to attain for the individual who is becoming ill. Asking for feedback of unique signs of impending illness from trusted friends or co-workers is a strategy used by some participants. These strategies facilitated confidence to catch hypomania early so it could be arrested and increased the likelihood of maintaining successful employment. Engaging co-workers, family or friends for support in recognizing the signs of hypomania offers one strategy that health care professionals can pass on to clients and families learning to live with BD. The use of feedback from others to assist in self-determination of employment capacity is for the employee with BDI.

The positive elements of hypomania mood symptoms, such as heightened energy, productivity or creativity (Michalak et al., 2005), were also noted by the participants of this employment study, however, they qualified that these tend to be temporary and lacked stability. There can be a tendency to disregard the potential downside of ideas generated during hypomania in the employment context. Some study participants said although their creativity and energy was productive the execution of employment tasks became less effective while hypomanic, although it may not be recognized at the time. Details could be

overlooked; alternatively excessive focus on some details could disrupt their performance of employment tasks.

The early employment experiences of many participants were negatively affected by delayed diagnosis. The length of time until BD diagnosis noted in previous studies can to take upwards of 10 years (Hirschfeld, Lewis, & Vornik, 2003), a delay corroborated by participants in the present study. Employment disruptions were not uncommon during this prediagnostic phase, leading to confusion and frequent job changes. This trajectory creates stress: for some participants stress is a precursor to hypomania, leading to a vicious cycle. Some life or employment stressors may be unavoidable however vigilant observation of avoidable stress is recommended. Proficiency in participant's abilities to detect hypomania improved over time and with employment experience. Various strategies were used to intercept hypomania. For some individuals adjustments in medication dose or increased rest or sleep were sufficient. Other participants evaluated their current life stressors and used social supports, meditation or exercise to address the stress. Weighing the short-lived positive employment effects of hypomania against the possible negative employment outcome of mania was "just not worth it" for most participants. Prevention of hypomania was the acknowledged best strategy. Given the deleterious employment impact the symptoms of mania can have, noted in this and other studies (Michalak et al., 2005; Tse & Yeats, 2002) a focus on recognizing and addressing treatment for hypomania intervention from a psychopharmacological and psychosocial perspective is imperative.

#### 3.3 Mania and its aftermath

Longitudinal studies of the affective symptoms of BDI indicate 48.4% experienced the spectrum of manic symptoms which can erupt periodically into a full blown mania (Dunner, 2003; Judd et al., 2002). Mania is a distinct relapse possibility for people who live with BDI. Participants in this study described the experience of mania while employed as highly disruptive. Once manic, it was next to impossible for the individual with BDI to control their behavior in the workplace and elsewhere. The person experiencing mania may be unable to explain their uncharacteristic behavior, and according to study participants, it is difficult for them to understand let alone explain to other people. For the most part they did not attempt to explain to supervisors or co-workers the cause of their displays of irritability, unusual

communication via email or in person, interpersonal conflicts, lack of judgment, or struggles to complete employment duties. However, there may be some merit to helping people with BDI explain illness behaviours, because of the consequences in the workplace. These were varied and included employment terminations, negative reactions from co-workers and management, and impulsive decisions to abandon employment. Personal and employment reputations were believed to be damaged from actions taken during episodes of mania.

Mania represents moods and behaviors frequently misunderstood by the general public. Wolkenstein and Meyer (2009) compared the attitudes of 188 young adults (aged 16-34) toward depression and mania. Their findings suggest that attitudes toward episodes of mania are significantly more negative than attitudes toward depression. The reluctance of the present study participants to discuss the impact of mania in employment may be related to enduring public perception. Psycho-educational support for employees and co-workers to better understand the specifics of mental illness at the employment site could possibly alleviate some of this effect (Gates, 2000). People living with BDI may benefit from learning how to educate and communicate with their employers and co-workers about mania, but this requires they disclose their illness. The impact of mood symptoms of BDI from the individual experiencing it are not often heard related to the impact on employment. Current available research reports that depressive symptoms are consistently and most significantly associated with employment disruption, while manic symptoms (mania or hypomania) have a variable impact on employment (Simon et al. 2008; Lam et al., 2010; Laxman et al., 2008). A novel finding from this study was the frequency of reports of the highly disruptive nature of mania on employment. Participants discussed the presence of low levels of depression (subclinical depression) which, although frustrating, were not viewed as significant enough to derail employment. One participant thought the medication may control the mania but left a low level depressive effect. Medication management is known as central to the effective management of BDI (Yatham et al., 2006). The fine-tuning of medication is critical and often time-consuming, yet necessary to support everyday occupations, including competitive employment. Employment disruptions were described by some participants as frequent and confusing when diagnosis was new and symptoms not well understood or treated.

The exploration of the employment impact of mania during research interviews promoted further consideration of the trajectory of the illness from an emotional perspective for some participants. The expressed emotional responses toward behavior during mania included remorse, embarrassment, guilt and intense regret. These feelings were described by participants as causative to the subsequent depression they experienced. A contributory issue to both the remorse and the depression may be the difficulty in accessing affordable, timely counseling and psychological support following a manic relapse. Some participants had accessed counselling and support services, however, reported the once available services were now permanently closed and unavailable. Descriptions of protracted employment absences are reported in the BD employment literature and indicate a time lag between symptomatic recovery and return to employment (Dickerson et al., 2010; Michalak et al. 2005). Therefore, understanding the range of possible treatment supports for a person who has experienced a manic episode is a significant pathway to assist in their recovery and return to daily function, including employment. The research evidence supports the adjunctive benefit of psychosocial support for this mental illness (Basco & Rush, 1996; Bauer, 2006; Colom et al., 2003; Miklowitz, 2008). Difficulties accessing psychological resources, the prohibitive cost to them as individuals, and the closure of some outpatient or community programs fuelled the emotional fallout of created by manic episodes for many participants of this study. This suggests ensuring adequate follow up treatment to address the emotional fallout of mania may be warranted for some people. There is a both a moral and economic imperative to remove these barriers to employment.

#### 3.4 Disclosure and stigma the entwined relationship in employment

Stigma in its various forms can discourage disclosure of a mental illness. This in turn can limit access to available support in employment circumstances. Most study participants spoke of past stigmatizing employment events. Examples of inadequate discussion or explanation prior to employment termination, the expression of negative attitudes from co-workers or outright discrimination against their BD condition were illustrated. This is exemplified by one employer statement "we would not consider you for a permanent position because of your illness." Stigma in employment setting was understood by participants by these types of

comments or described as nuanced in social situations that were difficult to definitively state as stigmatizing, however were perceived this way.

Disclosure experiences for some participants led directly to job loss. This led to non-disclosure in future employment. This was not a universal experience as two participants' disclosure was met with support, due primarily to employers who had previous experience with mental illness among family members or others in the community. This finding corresponds with research showing that personal contact with people who live with a mental illness is the most effective way of reducing stigma (Corrigan & Watson, 2002; Hinshaw & Cichetti, 2000; Livingston & Boyd, 2010). Two participants elected to disclose to their immediate supervisor, ensuring that, should their illness symptoms surface at work, someone in a leadership position was aware. For both individuals, the response received from their supervisor was surprisingly positive, creating immense relief given the 6-7 year wait prior to their disclosure. Public education is one way to work toward this positive outcome for more people living with BD.

In the employment context disclosure takes on different implications. The employment policies specific to persons with disabilities in Canada are relatively recent. The Canadian equal opportunity legislation (2006) provides guidelines to protect employees with mental health issues in the workplace. Policy guidelines set criteria for employers, however, as one participant stated "no matter how much policy is put in place, I raise no red flags" referring to a reluctance to disclose mental illness in employment contexts. For two of the participants their employment as peer support workers designates they live with a mental illness thereby disclosure is not necessary. Having a mental illness is implicit in their job title. This highlights the inextricably complex weaving of stigma, disclosure, and duty to accommodate when aiming to improve employment for those living with mental illness. Legislated duty to accommodate has a longer history in the United States (US). The ADA, first passed in 1990, is the US equivalent of the Canadian legislation. An American study of workplace accommodation for persons with schizophrenia in a rehabilitation supported employment program revealed 45% of study participants were not aware of their rights under the ADA legislation. Of those aware of their right to job accommodation, none accessed the opportunity (Gioia & Brekke, 2003). Although this study is specific to the American context and people with schizophrenia, it suggests governmental policy may not translate into accessing employment accommodation. Findings from the present study were similar. Participants with BDI were uncertain of the meaning or value of employment accommodation. The one study participant with employment accommodation worked for a large federal employer where employment modifications were provided for employees with a variety of disabilities. Support for judicious disclosure as suggested by Tse and Yeats in 2002, remains a reasonable recommendation today for persons with mental illness.

The past negative, stigmatizing employment events for some participants appeared to have a cumulative impact. For some participants with BDI stigma was experienced over the course of many years both in employment and personally. This could lead to a resignation and loss of confidence for some participants, presenting a link to internalized stigma. Self stigma or internalized stigma refers to the endorsement of a self perception based on the stereotypical or negative public perceptions of a stigmatized human condition, such as a mental illness (Corrigan & Watson, 2002; Scambler, 2009). Participants recounted both direct negative comments and implied statements or attitudes they considered negative. These experiences anticipated or assumed a negative reaction from others, led to non-disclosure in employment contexts, and self-stigma for the many study participants. This form of stigma occurs when ones identity is negatively impacted by the endorsement or anticipation of negative social beliefs or stereotypes.

Past research conducted with people living with BD has portrayed the development of negative self concept as a common illness response. However recent research supports a varied, contextualized and individual response to living with BD which, for some individuals can be positive or empowering as opposed to negative or anxiety provoking (Michalak et al. 2011). The present findings supports this variation: some participants chose to keep quiet about their BD and a tendency to isolate, others worked in an environment where their mental illness was automatically disclosed (consumer positions), and others had determined over time to disregard stigmatizing or negative comments.

A noted employment reaction known as underemployment refers to employment in positions less than their experience or economic need (Bowden, 2005). Underemployment as seen in

the present study corresponded to some participants' reluctance to embark on employment or career change remaining in employment considered safe although financially less desirable. Adding more context however is the reality of lost benefits and wages related to employment changes later in one's employment life. Underemployment is frequently considered in a negative light however this is not always the case. One participant explained that she could "do her job with her eyes closed" thereby reducing stress and improving self confidence in her abilities. Employment and career played a lesser role in her life goals while another participant thought her potential for career choice was significantly limited and her socioeconomic options similarly reduced. Self limiting perception is recognized to be connected to the extensive evidence which supports the reality of stigma faced by people with mental illness.

The sands of stigma however may be showing some signs of shifting for those with BD. Increasing personal accounts coming from public figures can potentially alter public perceptions. The voluntary disclosure of mental illness by well known figures, such as Margaret Trudeau, can help normalize mental illness. Providing accurate health care information in this context can further public education (Nairn & Coverdale, 2005; Stuart, 2006). The public perception and stigma impact of historical issues related to mental illness still echoes today and the shifts may be slow to fully benefit the people living with mental illness. The people who are living with mental illness however seem to be recognizing their potential and the strength and momentum of the recovery movement may support stigma reduction for persons with mental illness.

### 3.5 Factors impacting competitive employment

This section of the discussion focuses on the employment interview questions related to strategies that can assist or compromise employment. Participants identified a range of factors from employment organization practices to the social environment to consider in light of their BDI. Employment organizational practices and environments are noted to have undergone considerable change in the last 30 – 40 years in the Western world (Sparks, Faragher & Cooper, 2001). Industrial globalization has radically influenced the function of many employment organization practices. Communication, information and technological advances represent some of these transformative alterations to employment (Sparks et al.,

2001). For the individual living with BDI the employment environment can have considerable health related implications. The majority of participants in this sample endorsed flexibility as a positive employment factor that aids in choosing and maintaining employment. Flexibility referred to organizational practices such as scheduling, methods for employment task performance and working relationships. Flexible alterations to organization employment practices potentially offer benefit to all employees (Grawitch, Gottschalk, & Munz, 2006). A study of over 3500 employed individuals presents a compelling business case for employers' consideration (Halpern, 2005). Although the findings were based on employees without an identified psychiatric condition, the reduction of stress is pertinent to people living with BDI. Flexibility was represented in scheduling work hours and appointments as well as provision of adequate vacation and leave time. The returns in investment for employers can include reduced health costs, increased commitment to the employer, fewer absences, fewer missed deadlines and diminished stress (Halpern, 2005). Flexible work policies represent one organizational practice which may in part alleviate stressors of contemporary life and assist employees with stress vulnerable illnesses such as BDI. Hence, this constitutes a policy which can be beneficial to employers, employees and persons with BDI.

Stressors within employment contexts are important considerations for persons with BDI. Pragmatic and often inexpensive alterations have been suggested for people with BD elsewhere (Montejano et al., 2005); interestingly, most of the recommended alterations suggested by Montejano and colleagues were being used by participants in the present study to manage employment demands. These employment accommodations have limited focus on the broader social issues in employment settings. The emotional demeanour, collegiality and interpersonal relationships, or the social environment in employment settings was identified by participants in the present study as central to the employment experience, and were influential in choosing to accept, remain in, or change employment situations. This finding corroborates Tse and Yeats's (2002) theory of the important role of the social environment at work and Gates's (2000) focus on the social aspect of employment environments. Social, environmental and individual issues are all at play in employment.

### 3.6 Taking charge of employment destiny - the importance of employment choice

The reality of living with BDI signifies a need for employment which can accommodate the unique needs of the person with the illness. Employment choice can play a preventative role in illness relapse by avoiding employment situations that are ill-suited or stress inducing for the individual with BDI. The "goodness of fit" theory proposed (Tse & Yeats, 2002) for vocational rehabilitation and people with BD was substantiated by participants' discussions of the importance of employment choice. One participant chose to leave a long term, professional position due to the constantly changing demands and deadlines which he likened to "being at the tail end of the whip." Another participant stated any employment which caused sleep disruption from conflict, time pressures, or shift work was immediately ruled out. Regularity of work hours aiding in sleep hygiene, the need to manage stress, and favorable co-worker relations were cited in employment interviews as critical factors influencing their choice of employment. Study participants described employment choices earlier in their careers were often made without knowing the full impact of BDI, speaking to the need for increased education or inclusion of employment topics in self-management programs. Using a pros and cons evaluative process may be a useful framework to apply to employment choices made by people living with BDI, in terms of matching the needs of their illness with the demands of their work. For this cohort of participants judicious employment decisions were made recognizing the importance of integrating employment with managing BDI. Nevertheless, some participants expressed regret at not having their dream job, while others accepted the limitations of living with BDI and making the best employment choice with this in mind.

Approximately half of the participants in the present study chose self-employment because of its flexibility. Three of those combined self-employment with government supported disability payments. However, this carries with it a disincentive to earn any more than the allowable government-regulated income limit, and provided a safety net in terms of financial stability along with health, dental, and transportation benefits. This represents a vicious circle for people who require periods of financial support and health care coverage yet are unable to work full time in order to access this through an employer. The disability payment system and its ties to health care benefits fail to recognize the episodic nature of BDI. The

complexity of applying for, accessing and managing the financial aid provided by the provincial and federal government in Canada were noted to be frustrating for those who opted for this choice, consistent with previous reports (CMHA, 2001).

Self-employment was chosen by some participants as their optimum employment situation. Self-employment is also representative of important principles for recovery from mental illness (Dunner et al., 2008). For some individuals with BDI this may be a viable employment choice, although it warrants careful consideration, because participants described how self-employment required considerable initiative and tenacity.

### 3.7 Practice implications

Trends in addressing mental health and employment have increasingly been directed on the role of employers, organizational employment practices, and the employment environment (Chu, Driscoll & Dwyer, 1997; Krupa, 2007; Montejano et al., 2005; Olsheski et al., 2002). There are persuasive reasons for employer involvement with BDI. First, the economic cost to employers for BD ranks among the highest of all mental illnesses (Goetzel et al., 2003). Direct economic costs include reduced productivity and employment absence. Indirect costs include presenteeism (being at work but unproductive) and associated costs for support services for loved ones impacted by the employee with BD (Montejano et al., 2005). The responsiveness of people in employment leadership positions can influence the social atmosphere toward the person with BDI. The findings of this study identified the broader determinants of employment and the social environment which can influence employment. Supervisors and managers can be central figures in the success or lack thereof in a person's employment. Components of employment support include the ability of the employee and supervisor to speak candidly regarding BD, accurate knowledge of mental illness issues and flexibility toward altering workplace demands. Easy access to accurate mental health education and information to support the supervisory role, and training about awareness of attitudes, legislation, disabilities and issues impacting disclosure and accommodation are suggested needs to support employers (Hatchard, 2008).

An added role identified for employers relates to educating staff about mental health issues and mental illnesses. The organization known as the economic round table established in

1998 by Canadian businessman Bill Wilkerson sponsored a comprehensive review of employment and mental illness. A role for employers identified by this review is promotion of prevention oriented educational programs and services, improving access to immediate assessment, counseling sessions and appropriate referrals to other needed services to assist employees with mental health issues. A substantive role has been suggested for employers to take action on mental health in the workplace. The economic and productivity impact for employers has been established, and numerous roles for employers suggested. The ability of employers to tackle some of the recommended issues also needs to be heard.

This leads to a potential role for health care providers. The 2006 Kirby report indicates there is a lack of collaborative communication within Canadian mental health services; there are silos or pockets of care in mental health care which can result in poor communication between service providers and a patchwork of service provision. For the individual living with a mental illness and those who support them it can be challenging to access the services to best meet their needs (Kirby, 2006). A preventative focus in mental health care may assist in employment maintenance for individuals with a mental illness, currently employed. The concentration for health care providers may be collaborative communication with clients and families and a focus on preventing recurrence of a relapse of the mental illness.

In a longitudinal (10 year) study of BD approximately 50% of people with bipolar illness showed sustained remission or some improvement (Goldberg & Harrow, 2004). The findings of my qualitative study highlight the potential for paid competitive employment with a sample of people with BDI who have attained some stability in their illness. The possibility for employment for people with BD represents an area ripe for exploration of rehabilitation potential.

Many mental health care teams and services have adopted recovery oriented service provision. Occupational therapists are commonly employed within these mental health services. An issue of particular practice relevance to occupational therapy relates to "consumer positions" – jobs created to recognize the role of people who live with mental illness in helping others with similar challenges. These positions at community mental health teams are primarily supervised by OT's. Two study participants discussed their employment

positions in the community mental health system in consumer positions. Due to my past involvement both as an OT and as a practice coordinator within the community mental health rehabilitation system, greater detail of these roles was not sought by myself nor offered by participants during employment interviews. The ability for mental health care to demonstrate relevant and valued employment opportunities which accommodate consumer positions is a practice issue which deserves further attention.

Another related mental health care issue is the widespread yet under reported nature of mental illness. Adopting recovery oriented service provision suggests health care providers are likely to be working alongside people with a mental illness. There are numerous accounts of stigmatizing experiences people with mental illness have received through health care experience as service users (Deegan, 1988; Kirby, 2006; Thornicroft, 2006). The Kirby report (2006) recommends that stigma issues first focus on health care professionals in Canada. Successful engagement in competitive employment is a function of the employment structure and socially constructed ambience of the interactions of co-workers and the type of communication and support perceived by the employee (Gates, 2000; Krupa, 2007; Tse & Yeats, 2002). It will be interesting to note future developments in our mental health care system employment culture and is suggested for a future research initiative.

#### 3.8 Strengths and limitations

This study's strength lies in the unique focus of understanding the concurrent experience of being employed while living with BDI, a chronic mental illness. Most employment studies identify the limitations associated with BD. Few examine the employment experience from the perspective of the person managing with BD, fewer still have looked specifically at BDI. This particular sample of participants represented a diverse array of employment experiences to draw from along with extensive experience managing bipolar illness. Another strength of this study relates to participants' ability to reflect on and engage in this project. These participants demonstrated an interest in understanding their illness, contributing to research and a willingness to describe their personal severe episodes with this illness. The study demonstrates the potential for recovery in this population of a valued social role, employment and participants provided a number of insights and strategies for altering employment outcomes from which healthcare practitioners, people who live with BD and their supporters

and employers might benefit. The volunteers participating in this study had recent competitive employment experience, mild symptoms at the time they were interviewed, and were capable of introspection related to employment and their illness. Consequently, findings should be applied cautiously to other individuals with BD experiencing a different constellation of symptoms or circumstances. In addition this represents an in depth perspective from employees with BDI. The descriptions of co-workers, employers, actions, and settings are from the perspective of the individual being interviewed. A broader picture of employment might be explored in future research by incorporating multiple perspectives.

Future research might also explore employment concerns from the perspective of people seeking or struggling with employment to supplement the current findings from currently/recently employed adults with BDI. This may provide further direction for mental health care. Another avenue for future employment research is to examine the broader determinants of employment success such as the employment organization practices and the social environment characteristics, both of which require critical review.

#### 3.9 Conclusion

This study set out to answer three research questions. In addressing the first research question, what are the employment experiences of people living with BDI, this sample demonstrated a wide, diverse range of job titles, employment settings, and both challenging and successful experiences in the workplace. Employment included lab technician, office manager, arts and entertainment positions, self-employment and contract work. These participants demonstrate that competitive employment is a viable and attainable goal for persons with BDI.

The second question focused on employment accommodation. Most participants had not accessed formal accommodation available through Canadian government policy. Many were unaware of its existence and most participants saw little value in enacting accommodations given their current employment situation.

The final research question explored informal strategies participants used to adapt to employment challenges. Recognizing and managing illness symptoms, careful employment

choices, and flexibility in tasks and scheduling and employer/co-worker support were predominant strategies for sustaining employment.

The completion of this thesis launches the next phase of the research plan: to share this information with others. Presentations, networking, and written publications will share findings with mental health consumers, their families, and professionals seeking to improve employment success for clients. The intent is to share the unique perspectives of the research participants allowing others to view the employment world through the experiences of individuals with BDI.

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# **Appendices**

# Appendix A Interview guide employment experiences

The key questions (bold) to be asked at each interview.

Can you tell me how you came to know you have BD?

- 1. When, if at all, did you first notice signs of BD?
- 2. What did you think it would mean for you and your life?
- 3. What did you think it would mean for you and your career?
- 4. How, if at all, has your view of what BD would mean for you changed?
- 5. Can you describe the employment you have had?
- 6. Can you tell me more about your present or last job?
- 7. Could you describe a typical work day?
- 8. Where do you see yourself in 2, 5, 10 years? will use appropriate number.
- 9. What helps you manage work? (key question)
- 10. Have certain jobs been a better fit than others?
- 11. Have you made different career or job choices because of BD?
- 12. Who are the people, or the rules/policies, or places at your workplace that affect you or your work? (positive or negative)
- 13. Who or What has been most helpful to you?
- 14. How has he/she been helpful?
- 15. Can you tell me about anything that has gotten in the way of working?(key question)
- 16. Could you describe the most important lessons you have learned through your employment experiences? ?(key question)
- 17. What do you think are the most important ways to manage work and BD?(key question)
  - 18. How did you discover or create these?
- 19. Have you had experiences before you were diagnosed with BD which affected how you manage at work? Can you describe this to me?
- **20.** Have your views on employment changed? How so?

# 21. If you could have a "dream" job what would it be?(key question)

- 22. Based on your experiences what advice would you give to someone who has just found out he/she has BD?
- 23. Is there anything you might add that has occurred to you during our time together?
- 24. Is there anything you would like to ask me?

Do you know of the Canadian equal rights act that allows for changes or accommodations at your work to accommodate for a mental or physical health condition? (optional)

# Appendix B Follow up telephone interview

- 1. Since we last spoke has anything else come to mind for you regarding employment or anything else we discussed
- 2. Can you tell me more about.... (any issues discussed requiring clarification)
- 3. Can you tell me what you think about...(any employment related strategies that may have been thought of following the interview)
- 4. In the interview you mentioned.... (any areas that may need further information or clarification)

# **Appendix C** Letter for participant feedback



#### THE UNIVERSITY OF BRITISH COLUMBIA

Jan. 24, 2011

### Employment experiences of people living with bipolar disorder

Dear

Thank you for your participation in the employment experiences research interviews conducted throughout 2010. I appreciate your time and willingness to share your perspective. I am writing to invite your feedback on the most common initial findings from this research.

After analyzing findings from 10 participants, there are three main ideas listed on the next pages. Please read these findings and consider responding to the following questions.

- 1. Which findings most reflect your experience?
- 2. Is there anything important missing?
- 3. Are there other thoughts you would like to share?

We welcome your feedback and want to provide the most accurate representation of employment issues. However, you are not obligated to comment; your response is completely voluntary. As with your participation in the employment interviews, responses remain confidential and the report of findings does not identify individual participants.

Thanks again for participating in this research project. Findings will be used to inform services and people living with bipolar disorder to support their employment goals.

Sincerely,

Sandra Hale

Graduate Student Employment Experiences Research (2010)

Dr. Catherine Backman (supervisor)

Tel. 604-822-7409 or e-mail catherine.backman@ubc.ca

## **Appendix D Candidate Themes**

There were three main categories of findings.

- 1) The experience of mania
- 2) Ideas about disclosing mental illness to employers and the resulting responses
- 3) Aspects of the job, the employer, and the employment environment that helped or presented challenges for employment. Short descriptions and quotes are included to help explain these findings. Not all of the data can be included in this short summary, and while I hope these themes capture employment experiences common to most participants, I may have missed something you consider very important. Feedback is welcome and will contribute toward completion of this project

Participant feedback of candidate themes and provisional findings

## 1) The experiences of mania in bipolar disorder type I

Hypomania was described as a precursor to a mania. Hypomania increases energy, productivity and creativity. These behaviors taken in the context of work performance may be seen as an asset by employers. For some participants these mood changes quickly led to mania for other fluctuations in mood lasted for longer time periods.

"They [the employer] worked with me and used my "bing" my pizzazzy-self to promote everything that they were doing." (Bill)

"I think the hypomania thing, it's not sustainable and it's not easy, it comes fast and it goes fast... It's like a sparkler, its whoosh and then it's gone, kind of energy "(Lucy)

In the early phases of BDI hypomania and its signs could continue unrecognized. Participants who developed understanding and detection of hypomania regarded it as a symptom not to be disregarded. Recognizing and stopping hypomania before it progresses to mania is a critical employment self management strategy. Participants recognized the damaging impact mania could have in employment situations, however they also explained once manic it may not be possible for them to control or manage. Understanding, caring, compassionate assistance to obtain treatment is beneficial though not always acquired at this point.

"...and I've been very fortunate because it's a large organization it has this health services and it is the nature of our job [dealing with people with mental illnesses]." (Carol)

Following a manic episode some participants described feeling guilt and shame of manic behaviors as a major contributor to the depression which followed. Often this was seen as actions, communication and behavior so uncharacteristic and inexplicable it was seen as too damaging to repair.

"You just destroy all your relationships; destroy your reputation, the people you work with, and all the people you go to school with...the depression had everything to do with the after math of the mania... that period of time I did a lot of things that I intensely regretted."

(Bob)

"I was embarrassed, my confidence was just shot... just shattered. I thought, career wise, it's over." (Pete)

# (2) Stigma and disclosure

Disclosure of BD in employment situations for some participants was an unpleasant, negative, highly stigmatizing experience. For some participants this led to non disclosure in future employment situations.

I told my immediate supervisor that I had bipolar disorder, a mood disorder and it was within that week that I was fired and I don't think that was a coincidence." (Claire)

Avoidance of open discussions with supervisor/managers limited opportunities to better understand BD and communicate a supportive approach in the employment environment. This reduced exploration of the ways work tasks could be altered to support the employee.

"It's between you and your doctor." (Ramona)

"At work I get the impression that they don't want to talk about stuff like this. They like looking good when they raise money for breast cancer, the heart thing, but mental health? No way...there's a void, there's nothing there." (Pete)

"I never felt overt stigma not at work...yet I think the ability to do my job was compromised but there wasn't any real assistance or active accommodation no one was open and really spoke about it." (Bob)

Some participants felt disclosure to be most worrying for them and after disclosing received an understanding stance from their supervisor. Some participants decided to use disclosure as a means to educate others, stating that there are many misunderstandings about BD and disclosing about them provided opportunity to dispel mistaken ideas. Frequently co workers would say they were familiar with the illness as a friend or family member also had BD.

"...he (boss) was really great, and apparently he's had a lot of depression in his family... it was just nice to share it with him." (Deb)

"...so I did (disclose) and I was so nervous and I was shaking and they (bosses) were wonderful (Lucy)."

3) Factors related to the job, the employer, and the employment environment that helped or presented challenges in employment situations.

The vast majority of participants discussed specific strategies that assist in managing employment demands and BDI. These included: clear communication of employment performance expectations, minimizing interruptions during work time and written planning, preparation and prioritization of employment activities. Flexibility was the most highly reported aspect of employment appreciated for managing work and BD. This was exemplified and discussed in numerous ways.

"...how it's set up (the workplace and tasks). It would just be a flexible environment, that's the more important thing." (Maria)

Consideration of past and present employment raised issues of job choice and type of employment environments. The environment and the right choice of employment suited to the unique needs of the individual were described by participants. Certain employment options have characteristics some participants described as unsuitable for dealing effectively with BDI. Unclear performance requirements, erratic work hours, shift work impacting sleep, numerous or varying work demands, high conflict or stressful environments were noted by a number of participants.

"High workplace demands that are inconsistent and at times unknown and that are always kind of moving around and switching (Bob)

"... I made the choice not to go into law because of the extremely long hours and also the confrontational nature of the work...our work environment generally we're all working for the same goal. You know supportive of one another." (Lucy)

Support within employment environments was seen by one participant as beneficial, however not generally practiced in her current environment.

"Creating a supportive workplace...by taking our breaks together and not eating at our desks, we used to have morning coffee and everyone stopped at the same time, building friendships at work was much easier." (Deb)

#### Appendix E

## Feedback received from participants

#### Bob

1) the importance of recognition and avoidance mania, as this is the most damaging to long term employment success and personal well being. 2) I thought that the factors related to the employment environment section did a good job of laying out both positive and negative factors.

employers to have a frank conversation with someone who is becoming manic, expressing concern and suggesting a clear course of action (eg time off if required). I think that this is often avoided, because of obvious potential difficulties, but it would seem to be potentially helpful, along the lines of clear communication.

#### Bill

The letter was honest and balanced I feel. It represented me as well.

#### Ed

The second and third categories are linked back to employment. Your first point, 'The Experience of mania', isn't in this heading. Should it be?

"I was embarrassed, my confidence was just shot... just shattered. I thought, career wise, it's over." (Pete) I like for point one

I don't see anything for point 2. Maybe this one in a stretch: "It's between you and your doctor." (Ramona)

"...how it's set up (the workplace and tasks). It would just be a flexible environment, that's the more important thing." (Maria) Is fine for point three.

#### Maria

That has not always been my experience; full-blown mania has hit me without any precursor state, or so rapidly that I couldn't identify a ramping-up phase.

There are some benefits to hypomania with energy and output, but it doesn't always mean high quality work. I've produced total wrecks (but fast!) that my employer had to have done over again by someone else, so really it wasted time, and can't be controlled. Also, hypo manic behavioral changes (i.e. hypersexuality, irritability, obliviousness) are off putting to people, especially at work where it breaches etiquette.

. Understanding, caring, compassionate assistance to obtain treatment is beneficial though not always acquired at this point.

Knowledgeable outside observation and interventions by others are critical.

- . Coworkers treat you differently and returning to work is difficult.
- "You just destroy all your relationships; destroy your reputation, the people you work with, and all the people you go to school with...the depression had everything to do with the after math of the mania... that period of time I did a lot of things that I intensely regretted." (Bob) [strongly agree! Echoes my experience]
- "I was embarrassed, my confidence was just shot... just shattered. I thought, career wise, it's over." (Pete)

"I destroyed careers when manic because I impulsively and impatiently quit jobs over irritations (things I could tolerate when not manic), with no thought to consequences. These 'F\* you I quit!' storming-out scenes have happened a few times, leaving me with a patchy resume and poor references. I've impulsively quit jobs for other manic reasons too, like believing I had to travel immediately to have a dream come true".

# (2) Stigma and disclosure

Disclosure of BD in employment situations for some participants was an unpleasant, negative, highly stigmatizing experience. For some participants this led to non disclosure in future employment situations.

I told my immediate supervisor that I had bipolar disorder, a mood disorder and it was within that week that I was fired and I don't think that was a coincidence." (Claire)

"I was openly denied all chances at a permanent job in my company after disclosing. The HR manager candidly said it was because I would take too much sick leave." The individual changes to completing work tasks included, minimizing interruptions during work time and written planning, preparation and prioritization of employment activities. Flexibility was the most highly reported aspect of employment appreciated for managing work and BD. This was exemplified and discussed in numerous ways.

"...how it's set up (the workplace and tasks). It would just be a flexible environment, that's the more important thing." (Maria)

"It's important that I be able to take time off when I need it, without notice (crises don't give me advance notice). My current employer allows this. The usual job flexibility that just means setting your own daily work hours, etc., doesn't work for me. When I'm ill, I need to take time off to go to hospital and recover, and can't do any work at all. Jobs that require scheduled face time (service industry, clerical work) or inflexible deadlines don't fit." (Maria)